STRATIFICATION OF FUNCTIONAL DECLINE AMONG COMMUNITY-DWELLING COPD DIAGNOSED OLDER ADULTS: THE JOURNEY FROM INDEPENDENT TO DEPENDENT- LIVING ENVIROMENT (JIDE) SCORE

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Abstract

In New Zealand 77% of people aged over 65 dwell in the community. Ageing is associated with development of chronic health conditions such as Chronic Obstructive Pulmonary Disease (COPD). COPD exacerbates functional decline -- reduction in ability to perform self-care activities of daily living (ADL), putting them at higher risk of requiring residential care. A search of the international literature reveals that while there is research into COPD and associated functional decline, and general literature on functional decline and entry to residential care, there is no research that establishes the relationship between all three: COPD, functional decline and entry to residential care. While functional decline may be exacerbated by COPD, and functional decline in an elderly person leads to higher risk of entry to aged residential care, the inter-relationship between COPD, functional decline and entry to aged residential care is unknown.

The aim of this study was to address this 'gap' by first, assessing the independent impact of functional decline on transition to aged residential care (ARC) for community-dwelling older adults with COPD after adjustment for all other potential confounding variables, based on interRAI home care assessment data, and second, on the basis of the identified risk factors, develop a risk stratification score (Journey from Independent to Dependent-living Environment: JIDE). The data for this study were obtained from 10, 377 community-dwelling New Zealand residents 65 years and above who were diagnosed with COPD, and assessed between 1st July 2012 and 26th January, 2016.

Likelihood of entry to aged residential care facilities for the COPD cohort of individuals were modelled using a multivariable logistic regression. The regression coefficients from the explanatory model were then used to develop the JIDE score. The score discrimination was assessed using the receiver operating characteristic (ROC) curve in which the AUC value was 0.64 indicting a moderate predictive strength. The findings of the study suggest for the COPD cohort, functional decline in activities of daily living was an independent risk factor for entry to ARC (OR: 1.30 , 95% CI: 1.14-1.49). Other variables that were independently associated with risk of entry to ARC included: higher levels of cognitive impairment (OR:1.28 , 95% CI: 1.21-1.35), loneliness (OR:1.29 , 95% CI: 1.12-1.49), a history of falls (OR: 1.36, 95% CI:1.20-1.54), being a Māori (OR: 0.39, 95% CI:0.30-0.50), being a Pasifika (OR: 0.16, 95% CI:0.08-0.27) and lower frequency of pain (OR: 0.89, 95% CI:0.84-0.94). The JIDE composite score was used to categorise community-dwelling older adults into four risk levels: low, mild, moderate and high. The high group (OR: 3.54, 95% CI: 2.71-4.66) had almost four times as much risk of entering residential as the low group (OR: 1.0).

Underlying chronic conditions such as COPD impacts ADL performance levels. When ADL performance level declines, community-dwelling older adults with COPD have a potentially higher risk of moving into ARC. The JIDE score shows the severity of the risk an elderly with COPD is exposed to. Supportive health strategy, service delivery and care plans can be incorporated as part of a comprehensive clinical assessment.

List of Abbreviations

ABS	Aggressive Behaviour Scale
ADL	Activity of Daily Living
ADLH	Activities of Daily Living Hierarchy Scale
ARC	Aged Residential Care
ARHSS	Aged Residential Hospital Specialist Service
ARRC	Age Related Residential Care
ATR	Assessment Treatment and Rehabilitation
CAP	Clinical Assessment Protocols
CAT	COPD Assessment Test
CDHB	Canterbury District Health Board
CGA	Comprehensive Geriatric Assessment
CHESS	Changes in Health, End-Stage Disease, Signs, and Symptoms
COPD	Chronic Obstructive Pulmonary Disease
CPI	Consumer Price Index
CPS	Cognitive Performance Scale
CPS2	Cognitive Performance Scale 2
CPSS	Contracted Care Payment System
DHB	District Health Board
DIVERT	Detection of Indicators and Vulnerabilities for Emergency Room Trip Scale
DSI	Depressive Severity Index
EU	European Union
FEV	Forced Expiratory Volume
FI	Faecal Incontinence
FVC	Forced Vital Capacity
GHSAS	Geriatric Hospital Special Assistance Scheme
GOLD	Global Initiative for Chronic Lung Disease
HARP	Hospital Admission Risk Profile
HEC	Human Ethics Committee
HFA	Health Funding Authority
HRQOL	Health-Related Quality of Life
IADL	Instrumental Activity of Daily Living

IADLI	Instrumental Activity of Daily Living Involvement Scale
ICF	International Classification of Function
ICU	Intensive Care Unit
interRAI	International Residents Assessment Instrument
interRAI-HC	International Residents Assessment Instrument-Home Care
IOM	Institute of Medicine
ISAR	Identification of Seniors at Risk
JIDE	Journey from Independent to Dependent-living Environment
LTC	Long Term Care
LTCF	Long Term Care Facility
MDS-RAI	Minimum Data Set-Resident Assessment Instrument
mMRC	Modified Medical Research Council
MMSE	Mini-Mental State Examination
MOH	Ministry of Health
NASC	Needs Assessment and Service Coordination services
NH	Nursing Home
NHI	National Health Index
NZGG	New Zealand Guidelines Group
OECD	Organisation for Economic Co-operation and Development
PSS	Positive Symptoms Scale
RHO	Risk of Harm to Others
RHS	Residential Home Services
RISE	Revised Index of Social Engagement
SCI	Self-Care Index
SNA	Support Needs Assessment
SoS	Severity of Self-harm
TAS	Technical Advisory Service
UI	Urinary Incontinence
WHO	World Health Organisation

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Acknowledgments

In my formative years, when my mother was bed ridden and on the verge of giving up life, I witnessed doctors providing care and comfort, despite inadequate clinical data. It dawned on me that a robust heath data base has a role to play in healthcare. This experience shifted my future educational and career plans towards big data in healthcare and instilled in me a passion for big data health research. I began to think what if everyone involved in health related outcomes work together not only to protect the population from horrible diseases but also to use big data as an aid to clinical decisions and care planning? As a young economics undergraduate, research areas of data mining and machine learning fascinated me but unfortunately, those research fields were not present in most Nigerian Universities.

After graduation from the university, I started working with Ecobank Trans International (ETI), a leading international financial institution in Africa as a system operations specialist. I was able to use big data to gain greater visibility into the banks' customer behaviour, assess probability of risk of clients in respect of the banks' products and ensure high level of compliance, internal audit and fraud-risk management practices. Every day at work, the mind boggling question always on my mind was if it can be done in the financial world, why not in healthcare? I was determined to explore answers to the question to the highest level of knowledge, igniting my lifelong passion again.

As fate would have it, I had the opportunity to study Health Economics and Technology as an ERASMUS postgraduate scholar in Europe where my skills as a big data health scientist were honed and ever since I have always been on the lookout for opportunities to apply my knowledge. I knew that moving into a doctorate program would give me more opportunities to learn and explore more in this field. The decision to study in New Zealand paid off as I was introduced to big data and interRAI by my potential supervisor. The opportunity to use the interRAI data - a wonderful research repository to develop a prognostic score completely aligns with my interest and motivation for research into the use of big data in health to inform policy and service delivery decisions.

I would like to extend my sincerest gratitude to my supervisors Dr Arindam Basu, Adjunct Professor Pauline Barnett and Dr Hamish Jamieson, for their patient encouragement, enthusiastic support, and never-ending supply of expert advice. My appreciation goes to Dr Arindam Basu for his advice and direction regarding the methodology of this study, for making the data suitable for analysis and for his patience in helping me understand the free and open-source R software for statistical computing. Thank you also to Adjunct Professor Pauline Barnett especially for her scientific advice and knowledge and many insightful discussions, suggestions and making the grammar of the thesis good to read. Dr Hamish Jamieson, this thesis wouldn't have been possible without your acceptance to access the interRAI data. I consider myself most fortunate to have my PhD supervised by three such eminent people and I am eternally grateful to them since this thesis would not have been possible without their supervision and constant support.

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Dedication

To you Adefolake ....I trust you without reservation and never have reasons to regret it.

CHAPTER ONE

Introduction

1.1 The Concept of Ageing

Ageing is defined as the intrinsic, inevitable, and irreversible age-related process of loss of viability and increase in vulnerability (Comfort et al., 1964). Some researchers have defined it as a progressive functional decline, or a gradual deterioration of physiological function with age, including a decrease in fecundity (Partridge & Mangel, 1999; López-Otín, Blasco, Partridge, Serrano, & Kroemer, 2013). The World Health Organisation (WHO) projects that the world's population of adults above the age of 65 years will grow from 524 million in 2010 to 2 billion in 2050, increasing from 12% to 22% of the total population (World Health Organization, 2015b).

Population ageing has been particularly advanced in developed countries or those with high income earnings. Japan has the largest proportion of aged people, with 33% of its citizens aged 60 years and over in 2015. Japan is followed by Germany (28% aged 60 years or over), Italy (28%) and Finland (27%). The WHO concluded that the ageing process has been propelled by changes in fertility and mortality as a result of economic growth. Other indicators of these changes include reductions in child mortality, improved access to education and employment, gender equality, sensible reproductive health and family planning, advancement in public health and medical technologies, and improved living conditions. As a result people lead healthier lives than ever before, especially into advanced ages (World Health Organization, 2015b).

Western countries have been the greatest beneficiaries of these changes. In the last one hundred years for example, there has been a demographic shift in the United States in terms of population age. The number of Americans ages 65 and older is projected to more than double from 46 million today to over 98 million by 2060, and the 65-and-older age group's share of the total population will rise to nearly 24 percent from 15 percent. Average U.S. life expectancy has increased from 68 years in 1950 to 79 years in 2013, in large part due to the reduction in mortality at older ages. This has been estimated to fuel a 75% rise in the number of Americans ages 65 and older requiring aged residential care, to about 2.3 million in 2030 from 1.3 million in 2010 (Mather, Jacobsen, & Pollard, 2015).

Many people in the European Union (EU) are increasingly older citizens and the growth in the numbers of people in this category has been dramatically referred to as a "silent revolution" (Walker, 1993). The European Union in 2018 reported that the share of the population aged 65 years and over is increasing in every EU Member State, EFTA country and candidate country (European Commission, 2018), with increases within the last decade ranging from 4.9 percentage points in both Malta and Finland to 0.3 percentage points in Luxembourg. On the other hand, the share of the population aged less than 15 years in the 28 EU countries population decreased by 0.2 percentage points. The report further noted the importance of the very old growing at a faster pace than any other age segment of the EU's population. The share of those aged 80 years or above in the European Union is projected to increase by two and a half times between 2018 and 2100, from 5.6% to 14.6% and those aged 65 years or over will account for 31.3% of the total population by 2100, compared with 19.8% in 2018 (European Commission, 2018).

Changing age group relationships within the elderly population in the developed world have led to new descriptions of this population. A major profile description in which the ageing population has been divided into three age groups was suggested by Riley and Suzman (1985). They categorised the older population into the young old (65-74), the middle old (75-85) and the oldest old (over 85). These groups are found in various parts of the community, in private homes, family homes or some type of accommodation suited for support in the later ages of life utilising health and support services as they undergo a gradual decline of physiological functions - a concept referred to as "ageing in place".

Ageing in place is a concept developed by health and social policy ministers from Organisation for Economic Co-operation and Development (OECD) countries. This concept refers to older people who require supported living being able to continue to live in their own home or where this is not possible to enable them to live in a sheltered supportive environment which is as close to their community as possible (World Health Organization, 2015b). This enables people to remain living in the community, with some level of independence, rather than in residential care (Davey, De Joux, Nana, & Arcus, 2004; Wiles, Leibing, Guberman, Reeve, & Allen, 2011). It has also been explained as the enablement of the elderly to maintain independence, autonomy and social support, including friends and family connection (Lawler, 2001; Keeling, 1999). Additionally, it has been said that having people remain in their homes and communities for as long as possible may avoid the costly option of institutional care and is therefore favoured

by policy makers, health providers, and by many older people themselves (World Health Organization, 2007).

1.2 Ageing in New Zealand

In New Zealand, the population has also changed. The main reasons for the ageing of New Zealand's population are declining fertility, the ageing of the baby boomer generation (people born between 1946-1964), and an increase in average life expectancy (Cornwall & Davey, 2004). Future estimates indicate that the population aged 65 and above (Figure 1.1) will increase to about 1.3 million by 2041 and possibly 1.8 million by 2068 (Statistics New Zealand, 2014). These projections come with the expectation that older people in New Zealand will live healthy, independent, connected and respected lives. The influx of migrants into New Zealand is an important factor that will also make the older population much more diverse. Up to 60,000 migrants per year have made New Zealand their home in the last few years and this is projected to increase in the future. Furthermore, the number of people of Māori descent aged 65 years and over is projected to increase by 115% in the next 15 years reaching the highest percentage by 2026. The older Pacific population is expected to grow in number by 110%, and the older Asian population by 203% in this same period (Statistics New Zealand, 2014). In terms of cost, an estimated 42% of the total health budget in New Zealand is spent on people 65 years and above and is estimated to rise to about 50% of District Health Board (DHB) expenditure in the next 10 years (Ministry of Health, 2016a).

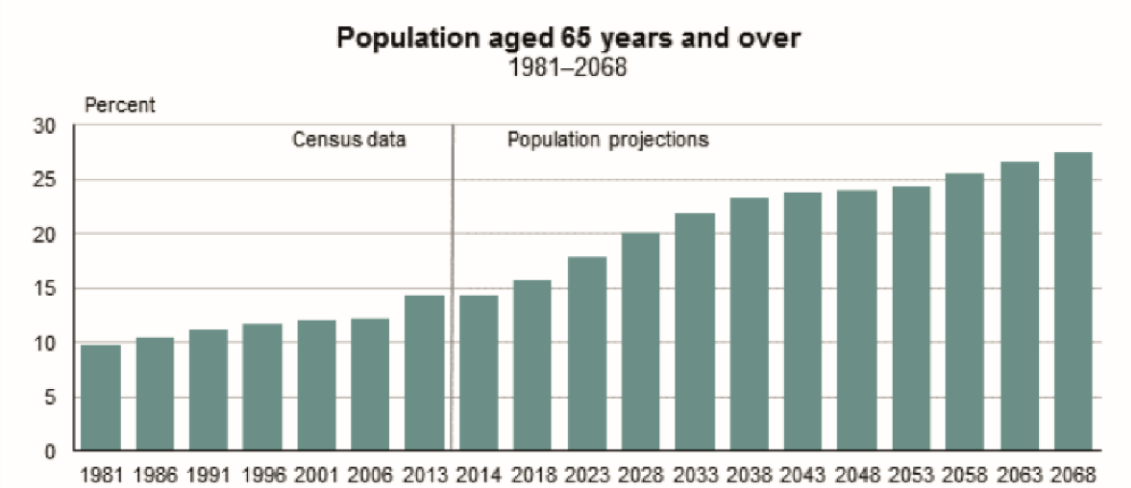

Figure 1.1: Population aged 65 years and over (1981-2068)

(Statistics New Zealand, 2014)

Spending on services for older people is increasing faster than other expenses. Over the last 10 years, DHB spending on services for older people has increased twice as fast as overall expenditure and five times as fast as the Consumer Price Index (CPI). Of the DHBs expenditure of 983 million dollars on support services for older people, 60% is allocated to aged residential care (Ministry of Health, 2016a).

In New Zealand, ageing in place policies have been implemented. The government, through the New Zealand Positive Ageing Strategy and Health of Older People Strategy, has proposed an integrated approach to health and disability support services. This is responsive to varied and changing needs, supports older people remaining in their own homes, reduces the need for institutional care and enhances their sense of independence and self-reliance (Dalziel, 2001; Dyson, 2001).

A considerable amount of progress has been made by the New Zealand government through the New Zealand Health Strategy, especially focusing on the community. The strategy, first enacted in 2002 and subsequently revised in 2016 has been basis for achieving more consistent and comprehensive assessment of the need for home and community support and residential care; establishing projects that improved older people's strength and balance including prevention of frailty, fracture and harmful falls; increasing mental well-being, mobility and quality of life for the aged. These achievements create a platform for better understanding the risk factors of poor health, social isolation and loneliness, and neurological conditions and a better knowledge of possible technologies to tackle them (Ministry of Health, 2016a). The successes achieved through these initiatives have led to the development of a new Health of Older People Strategy to cater for the next 10 years of ageing in New Zealand (Ministry of Health, 2016a). This strategy demonstrates a new direction, with a strong focus on prevention, the promotion of independence and wellness, people-centred services, trust, cohesion and collaboration, and integrated social responses, for the older proportion of the population.

The ageing process, however is often accompanied by the development and manifestation of chronic health conditions such as Chronic Obstructive Pulmonary Disease (COPD) and other challenges that require daily support. Hence, considering the self-sufficiency of the older person in the community becomes an urgent public health concern (Guralnik, Fried, & Salive, 1996). Many older people enter residential care when their functional ability declines and they are no longer able to manage living in their home environment, especially in the face

of chronic conditions. Many factors contribute to the decision to enter residential care such as cognition, activities of daily living, ethnicity, loneliness, history of falls, instrumental activities of daily living, age, living arrangement, gender, and disease condition such as COPD. COPD is a significant cause of death and its prevalence increases with ageing. It exacerbates a number of problems that burden older adults, such as functional decline (Eisner et al., 2008), caused primarily through the loss of activities of daily living. In addition, cognitive impairment, which is characterised by memory loss among older adults is a significant concern (Tabert et al., 2002). Hence, decisions about the need for transition to institutional or community living, or maintaining quality of life through supportive services are important responses to the process of functional decline for the aged experiencing aggravated chronic conditions, such as COPD (Guralnik et al., 1996).

1.3 Chronic Condition: COPD

Well known chronic diseases include chronic heart disease, diabetes mellitus, stroke, and COPD. Together they represent the leading causes of mortality representing 60% of all deaths worldwide (World Health Organization, 2015a). Additionally, 50% of those who died from chronic diseases were under 70 years and of the 35 million individuals who suffer from chronic disease, 50% were women (World Health Organization, 2015a).

COPD is a general term used to characterise diseases of the lungs that are chronic and cause airflow restrictions. The most pronounced symptoms include chronic cough (persistent cough for three months), excessive release of sputum and gasping for air. It represents an alarming disease of the lung that may over the time result in death. Often COPD is under diagnosed, and not recognised in time for the best or most optimal management to be implemented. Risk factors for COPD include exposure to uncontrolled tobacco smoking, air pollution and occupational dusts and chemicals, with the WHO classifying tobacco smoking as the greatest risk factor among high income countries while air pollution represents the biggest risk factor among less developed, developing and low income countries (World Health Organization, 2015a). Based on WHO estimates, the population suffering from moderate to severe COPD is about 65 million worldwide and, as at 2005, 5% of overall deaths were from COPD. It was the fifth leading cause of death in 2002 and unless urgent preventive steps are taken, COPD is estimated to become the third leading cause of death worldwide by 2030 (World Health Organization, 2005; Mathers & Loncar, 2006; Strong, Mathers, Leeder, & Beaglehole, 2005).

The WHO recognises the severity of the situation posed by COPD, putting in place strategies to coordinate global efforts to reduce the toll of the disease including disability and premature death. The core focus of these strategies are: to increase awareness of the disease so that the public and health professionals recognise the disease and are aware of the associated problems; to organise and co-ordinate epidemiological surveillance to monitor global and regional trends in COPD; and to develop and implement an optimal strategy for its management and prevention (World Health Organization, 2015a).

1.4 COPD in New Zealand

In New Zealand, COPD represents a significant disease that has high morbidity and risk of death. It is estimated to affect 15% of all New Zealanders aged over 45 years and is often under diagnosed. It is the fourth leading cause of death behind cancer, heart disease and stroke (Broad & Jackson, 2003). Previous research has shown that it caused 6% of all deaths in the country making it the fourth leading cause of death in 2002 (Davis et al., 2002). Dust exposure as a result of occupational activities and smoking cannabis and tobacco have been responsible for about 85% of COPD incidences in New Zealand (Town, Taylor, Garrett, & Patterson, 2003). Several other health conditions may arise due to COPD progression and lead to further reduction in the quality of life (Katz et al., 2010; Schnell et al., 2012).

For the New Zealand health system, it is a major public health concern with substantive burden (Milne & Beasley, 2015). This burden is much more pronounced among the elderly, those of low socio-economic status, and rural dwellers. In a study to investigate the impact of respiratory disease in New Zealand, the 2018 update conducted by Barnard and Zhang (2018), COPD mortality rates were found to be similar for men and women in the 45-64 years age group, but higher in men than in women in the 65 years and above age group in 2015.

Barnard & Zhang (2018) reported COPD incidence and progression was rapid among the Māori and Pacific communities; mortality rates were highest among Māori, whose rate of 183.4 deaths per 100,000 people per year was 2.24 (95% CI 2.07-2.42) times higher than 81.9 rate for non-Māori. In separate studies, the risk of death among Māori was found to be 70% greater than for other ethnic groups (Glover et al., 2013; Bramley, Hebert, Tuzzio, & Chassin, 2005). In terms of hospitalisation, Barnard and Zhang (2018) found the rates are highest for Māori and Pasifika, at more than three times other ethnic groups in the country. The authors reported that adult

mortality resulting from COPD for Māori is about twice that of other ethnic groups, closely followed by Pasifika and within the elderly population COPD mortality is twice as high when compared to other ethnic groups. COPD mortality also increases with increasing socio-economic deprivation, with deaths occurring at 2.26 times the rate in lower quintile. Increasing COPD mortality with increasing deprivation was significant for both Māori and non-Māori but not significant for Pacific or Asian peoples.

COPD is not curable. However, available medical and physical treatments can help relieve symptoms, improve exercise capacity and quality of life and reduce the risk of death. In addition, the effect of these treatments can be very important in the life of the elderly. If the conditions are not properly managed, the result may be functional decline. As noted above 15% of all New Zealanders 45 years and above suffer from COPD. These are the people expected to become part of the 1.8 million aged 65 years and above in the next 20-50 years. Additionally, New Zealand has a comprehensive interRAI database that captures information about older adults who are 65 years and above, and from these database, 15% of all older adult assessed have a confirmed COPD diagnosis. On the basis of projected incidence, prevalence and burden of disease specific to 65+ age group, it is reasonable to focus on COPD rather than other diseases.

1.5 Ageing, Functional Decline and COPD

Functional decline is a reduction in ability to perform ADL, often from the presence of new disabilities which arise from a decrease in ADL. (Lee, Ross, & Tracy, 2001; Hastings & Heflin, 2005). They have a significant relationship with mortality, loss of independence, frequent visits to hospital and entry into ARC (Fried et al., 1998; Stuck et al., 1999). For any society with a significant number of older people, functional decline places a burden on economic and societal resources. In the United State for example, 26.1 million adults aged 65 and above have a least one basic action difficulty or complex activity limitation; this represent 60.5% of all adults of 65 and above years (National Centre for Health Statistics , 2016).

Ageing and functional decline are inter-related (Guralnik, LaCroix, Branch, Kasl, & Wallace, 1991). In addition, the type of functional decline is affected by the type of health conditions among those who have chronic aggravations such as COPD (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Wolinsky & Tierney, 1998). Essential for a good quality of life is having

functional physical ability. However, among the elderly there is high prevalence of dependence among those with chronic disease. In order to ensure that the burden due to the size of the population does not increase in the future, there needs to be an increase in active life policies and strategies. A more direct and engaging pathway is needed to find ways of reducing the influence of ageing and disease despite the fact that diseases will continue to exist among the elderly in the face of physiological changes and environmental risks.

Evidence from the literature suggests that the maintenance of certain activities in daily living can alter and improve functional capacity in the elderly, despite the presence of health conditions such as COPD (Bruce, 1985), and may delay the start and progression of functional outcomes of chronic diseases (Fries,2002). The symptoms of COPD may interfere with many aspects of daily living and greatly impact on health through functional impairment, a reduction in the quality of life and a requirement for prolonged assistance including risk the of severe decline or becoming dependent on others for performing ADL (Rodrigues, Matias, Oliveira, Vacas, & Botelho, 2015). Other studies have found that the presence of COPD is often accompanied by other manifestations including cardiovascular disease, skeletal muscle wasting, cachexia, and normocytic anemia (Divo et al., 2012; Decramer & Janssens, 2013). In contrast to the manifestation of COPD and associated co-morbidities, functional decline represents the loss of physical abilities (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013) and is associated with loss of independence, and ultimately death (Fried, 2001). Those with COPD experience progressive dyspnea and exercise intolerance which limits their ability to carry out activities of daily living (ADL) (Ries et al., 2007; Pauwels et al., 2001). ADLs are simple activities that are essential for an independent life such as self-care (showering, dressing, grooming) and basic mobility. Instrumental activities of daily living (IADL) are more complex activities and require higher functioning such as preparing meals, handling finances, home maintenance, shopping and travelling alone (Janaudis-Ferreira, Beauchamp, Robles, Goldstein, & Brooks, 2014). COPD is closely related to functional decline with shared risk factors such as ageing and smoking and common mechanisms of deregulated inflammation and endocrine dysfunction (Fragoso, Enright, McAvay, Van Ness, & Gill, 2012; Lahousse et al., 2015).

Disability among individuals who have COPD is often much more pronounced than for those who do not have this condition. COPD exacerbates functional decline because sufferers have more difficulty in managing money, doing household chores, preparing their own meals,

feeding, and dressing themselves, and have a greater need for health services (Park, Richardson, Holleman, & Larson, 2013). Such disability can also cause severe anxiety and depression (Stuart, Rogers, Balanos, & Wood, 2011; Borak, Chodosowska, Matuszewski, & Zielinski, 1998; Eiser, West, Evans, Jeffers, & Quirk, 1997), which can subsequently cause further decline in the activities of daily living (ADL) and affect the Health-Related Quality of Life (HRQOL) (Goto et al., 2004). A Dutch study aimed at assessing the occurrence and risk factors of chronic diseases and disability in the elderly, found that participants with COPD were more than twice as likely to experience functional decline when adjusted for age, sex, smoking, and co-morbidities and that there was a stronger association in COPD participants with severe airflow limitation, with frequent exacerbations, and more symptoms. The results further suggested that with increasing COPD severity of airflow limitation those elderly who have declined in function experienced greater levels of decline (Lahousse et al., 2015).

As life expectancy increases for this elderly cohort, the quality of those additional years can vary greatly from person to person due to chronic conditions such as COPD. At some point, the elderly may experience functional decline that would hinder independent living and require long-term services and supports. At this point, every older person should be assessed with instruments that can capture functional status before, during or after experiencing functional loss that might lead to ARC entry. One of such instrument used is interRAI.

1.6 Assessing elderly health in New Zealand: the role of interRAI

1.6.1 Historical background to interRAI.

The development of interRAI started in the late 1980s in the United States (Carpenter & Hirdes, 2013), after reports of inadequate care of the elderly. In 1986 the Institute of Medicine (IOM) recommended the development of a standardised and comprehensive resident assessment system able to measure and compare residents' progress over a period of time and between organisations, in order to monitor and improve the quality of care. Within a year, the Minimum Data Set-Resident Assessment Instrument (MDS-RAI) became a federally mandated system as part of a comprehensive set of nursing home reforms passed by the US Congress (Hawes, Vladeck, Morris, Phillips, & Fredeking, 2003; Fries & Fahey, 2003). Over the years the instruments were adopted internationally and renamed "interRAI".

Since 1992, the interRAI vision statement has been: the assembly of accurate clinical information in a common format within and across services sectors and countries enhances

both the well-being of frail persons and the efficient and equitable distribution of resources (Fries & Fahey, 2003). Currently, interRAI is a collaborative network of researchers and practitioners in over 35 countries committed to improving care for persons who are disabled or who have medically complex conditions. The improvement of care is based on the promotion of evidence-informed clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of persons served across a variety of health and social services settings. Several interRAI instruments such as the interRAI Home Care instrument, have been developed using common measures that refer to the same clinical concept in different population settings (interRAI, 2018).

The International Residents Assessment Instrument-Home Care (interRAI-HC) has been designed to be a user-friendly, reliable, person-centred assessment system that guides comprehensive care and service planning in community based settings. It focuses on the person's functioning and quality of life by assessing needs, strengths, and preferences and facilitates referrals when appropriate. When used over time, it provides the basis for an outcome-based assessment of the person's response to care or services. The interRAI HC can be used to assess people with chronic needs for care as well as those with post-acute care needs. It supports a variety of research-informed decision support tools that assist the assessor in planning and monitoring care. Strategies to address problem conditions are triggered by one or more Home Care item responses, and include screening systems to identify appropriate outreach and care pathways for prospective clients, a quality monitoring system, and a case-mix system that creates distinct service-use intensity categories (interRAI New Zealand, 2018b).

Instruments developed by interRAI has been proven to be reliable and valid. Hirdes et al., (2008) assessed the reliability of items from five interRAI instruments; home care, long term care, mental health, palliative care, and post-acute care, across 12 countries. They reported the overall mean kappa, a measure for inter-rater reliability, for 161 total items captured in the interRAI instrument. These items are common to at least two of the five instruments, and reported to be about 0.75. The mean *kappa* for specialised items varied among instruments from 0.63 to 0.73. The *k*-statistic for over 60% of more than 160 items used in interRAI instruments are more than 0.70.

In the context of New Zealand, reliability of the interRAI instrument has been established in the Bay of Plenty study (Parsons et al., 2013). The study compared interRAI-HC with an existing geriatric protocol, the Support Needs Assessment (SNA), in community-dwelling older people in a randomised controlled trial of 316 people (65+) referred for assessment of needs with follow-up at 1 and 4 months. The authors reported that significantly more support needs were identified using the interRAI-HC than with the SNA (Parsons et al., 2013).

Additionally, the interRAI-HC instrument was found to have generally good psychometric properties and a 99.8% match to mortality data ensuing high data reliability in a study that described the national interRAI-HC population, assessed its data quality and evaluated its ability to be matched within New Zealand (Schluter et al., 2016). These interRAI instruments have been used to measure functional decline and other factors that may become potential risks factors of aged residential care entry among community dwelling older adults.

1.6.2 The decision for a national system.

In New Zealand, the need for a validated and comprehensive assessment process was first recognised with the introduction in 1994 of Needs Coordination (now called Needs Assessment and Service Coordination services (NASC)) (Ministry of Health, 2004). A decade later, in 2004, the Guideline for Specialist Health Services for Older People reinforced this need when the New Zealand Guidelines Group was commissioned by the Ministry of Health to develop an evidence based assessment pathway.

The Guidelines Group (NZGG 2003) reported that the standardisation of assessment procedures across New Zealand was essential, and that assessment of older people should be sufficiently comprehensive to lead to services that improve the health and well-being of older people and their carers. Proactive assessment should follow referral or the presence of risk factors or contact with health and social services. Following assessment, the assessor works with the older person to develop a treatment/management plan that includes carers and care recipients, and involves timely intervention and regular follow-up. Standard assessment tools and methods of collecting, reporting and comparing data should be part of a comprehensive system, and assessors should be specially trained.

Additionally, it was reported that older Māori and Pacific people and some people with known disabilities have lower life expectancies and should be eligible for assessment at age 55. Assessors fluent in te reo Māori should be available to Māori, when preferred, and assessors of

Pacific people should, as far, as possible, speak the same language and the same ethnic background as the person assessed.

The NZGG commissioned the University of Otago to evaluate four leading assessment tools used internationally. This evaluation concluded that the interRAI-HC assessment was the best tool available for delivering consistent assessment and standardised data in most of the domains identified by the NZGG and could be considered the 'gold-standard' of assessment tools. Time and effort is required to train assessors, but once people are trained, it produces very good results and provides insights into important clinical and social issues (Martin & Martin, 2003).

A pilot study using the interRAI instrument was conducted between 2004 and 2007 in five DHBs around New Zealand. An outcome of an evaluation of the pilot study (Parsons et al., 2013) led to a four-year roll-out of the interRAI-HC and Contact Assessments (National interRAI Training Service, 2015) from 2008 to 2012 across all 20 District Health Boards. It has been mandatory since July 2012 for people aged 65 and over to have an International Residents Assessment Instrument (interRAI) clinical assessment completed in order to access publicly funded home based support services or for entry into aged residential care. The rollout to all DHBs using interRAI-HC for their community clients was completed in 2013 (Ministry of Health, 2016a; Vuorinen, 2017).

New Zealand is the only country in the world that has a national, mandated assessment tool for access to publicly funded services. This tool supports the strategic themes of the 2016 New Zealand Health Strategy. The interRAI-HC has been used to collect vital information within community based populations, includes older and disabled adults at risk of admission to aged residential care or requiring long term supports. The national coverage of this tool in New Zealand has not only allowed it to aid clinical practice and identify appropriate services packages such as home or residential care but also to be a research tool that allows data to be linked by a unique National Health Number(NHI) to other data bases such as hospitalisation, mortality and pharmaceutical use. By 2016, the interRAI-HC data base comprised 105,502 total assessments, of which 78,789 were first home care assessment. This data base is continually updated with new home care assessments and subsequent follow-up annual assessment and can prove immensely useful for population level studies.

1. 7 Need for Prognostic Stratification

One concern that an ageing population raises for policy makers in developed countries is the effect on the economy. Historically, an assumption often made is that as people get older they become less healthy with increased functional disability and consequently require more costly assistance (Miller, 2001). Furthermore, Jacobs (2010) reported in his research that trends in New Zealand up until the turn of the century indicated that disability levels were not reducing and that the likelihood of functional disability and the need for long-term care increases with age.

Research into functional decline among the elderly in the community who have COPD is of utmost importance in New Zealand because approximately 77% individuals aged 65 and above live in private dwellings within the community. Within this group are those who suffer from chronic conditions and, because of their age, are prone to functional decline. There is the need to generate valid and reliable prognostic score that can accurately measure functional decline in the face of many uncertainties. Prognosis is at the centre of decision making, and the relationship between baseline risk factors and co-varying outcomes from the assessment of prognostic factors represents a major objective in health research (Halabi & Owzar, 2010).

Approaches to measuring functional decline are varied. Several studies have looked into prognostic risk of functional decline in terms of mortality. The circumstances under which mortality-based risk stratification has been undertaken are problematic because mortality does not necessarily represent the most instructive index of health challenges in the older population. Other models have focused on acute situations, pre- and post-hospitalisation, intensive care and emergencies. On pre-hospitalisation, Palleschi et al. (2013) considered the functional decline of patients before being hospitalised. Acute medical illness during hospitalisation was used to develop the Hospital Admission Risk Profile (HARP) model to measure the risk of developing functional decline in the elderly three months after hospital discharge (Sager et al., 1996). The study concluded that older age, lower ADL and cognitive impairment were the independent predictors of functional decline. Many existing prognostic measures have been set up to address mortality, hospitalisation, acute care and validity of interRAI instrument among many concerns. However, if older adults with COPD experience functional decline, can they continue to live in their homes or move into residential care? There is need to develop a measure that presents living options to older adults and not necessarily medical care or adverse outcomes.

This is an important concern this research sought to provide with the development of a new prognostic measure.

Additionally, what happens with the aged who are living with chronic conditions? From their inception, chronic conditions are lifelong. Considering COPD as a significant prevalent and debilitating chronic condition with aggravation phases as described above, what could be the prognosis for the older adult with COPD? In case of an older adult with COPD in New Zealand, what is the likelihood of entry into aged residential care from the community? A search of the international literature reveals research into COPD and associated functional decline, and general research into functional decline and entry to residential care, but there is no research that established the relationship between all three: COPD, functional decline and entry to residential care. While functional decline may be exacerbated by COPD and functional decline in an elderly person leads to higher risk of entry to aged residential care, the inter-relationship between COPD, functional decline and entry to aged residential care is unknown.

Fortunately, the availability of the interRAI-HC assessment and the ensuing data set provides an excellent opportunity in New Zealand to examine COPD, functional decline and the prospect of entry into aged residential care.

1.8 Study Objectives

The goal of the thesis is to assess the role of functional decline as risk factor for ARC admission among community-dwelling COPD elderly and on the basis of the identified risk factors, develop a risk stratification score. To achieve this goal, four research objectives are set;

1. Test the hypothesis that those with better ADL capabilities were less likely to enter ARC after controlling for all other potential confounding variables.
2. Develop a risk stratification score based on the predictive ability of associated variables that contributed to ARC entry. The composite score characterises the 'Journey from an Independent to a Dependent Living Environment' and is given the acronym 'JIDE score'.
3. Assess the incremental risk of ARC entry based on the JIDE score.
4. Test the hypothesis that those with better ADL capabilities have reduced hazard of ARC entry after controlling for all other potential confounding variables.

1.9 Thesis outline

In order to achieve the study objectives, the thesis is structured as follows:

- Chapter 2 gives further information about previous research into the factors that explain why community dwelling older adults transition into aged residential care and the experiences of stratification into risk groups.
- Chapter 3 presents the methodology and the steps undertaken in the conduct of the study.
- Chapter 4 presents the results of the analyses performed on the data set.
- Chapter 5 discusses the implications of the findings and compares and contrasts the result with other findings.
- Chapter 6 concludes the thesis by presenting recommendations for future research and practice.

CHAPTER TWO

Literature Review

As discussed in Section 1.1, the population of New Zealand is ageing, with the presence of chronic conditions including COPD which affects more than 15% of people 45 years and older. This condition has brought about issues associated with functional decline. As the interRAI-HC instrument provides a way to assess the situation of people living in the community, using this assessment instrument it is possible for prognostic scores as discussed in Section 2.5 to be modelled and used to assess the risk of ARC entry based on certain covariates. The review of the literature in this chapter as set out in the next paragraph provides a background to the elements of this research.

The literature chapter is divided into six sections. Section 2.1 provides an overview of the strategy used in sourcing research materials relevant to the study. In Section 2.2, there is a detailed description of the evolution and history of Aged Residential Care (ARC) in New Zealand. The relationship between COPD and functional decline based on previous research is discussed in Section 2.3. Section 2.4 describes in detail the risk factors for residential care entry while prognostic scores based on the predictors of residential care admission are discussed in Section 2.5. Section 2.6 provides a critical overview of the literature.

2.1 Criteria and Strategy

The electronic databases used in the literature search were Google Scholar, Google, PubMed database, the Ministry of Health web page (Ministry of Health), interRAI national and local websites and MultiSearch (University of Canterbury electronic database). Additionally, other articles not indexed in these databases were sought through medical, nursing, psychology and allied health databases. A key strategy used in the literature search was the snowball approach, using sourced documents to identify and locate additional literature (Wohlin, 2014). In searching for relevant documents, key terms and phrases were used independently or combined using “Boolean logic”. In most cases, key terms in the literature search included ‘aged’, ‘interRAI’, ‘COPD’, ‘functional decline’, ‘residential care’, ‘Activity of Daily Living’, ‘IADL’, ‘cognition’, ‘loneliness’, ‘pain’, ‘admission’, ‘depression’, ‘community-dwelling’ and ‘risk factors’. Publications, reports and books by the Ministry of Health and Ministry of Social

Development were used as resources. During the literature search, the relevance of documents were informed by their abstracts or titles based on the criteria for inclusion/exclusion.

The inclusion criteria included, firstly, articles or documents with key words such as 'COPD', 'functional decline', 'aged', 'elderly', 'older people', 'over 65 years' and 'interRAI'. Secondly, the article had to refer to the older people who have under- gone interRAI assessment, experienced loss of ADLs, were in need of substantial levels of support or long-term support, either at home or within residential care. To keep track of relevant literature, documents and papers were imported and stored using 'Mendeley', (https://www.mendeley.com) and where documents were specifically recommended by supervisors, they were kept in Slack (https://slack.com/), a platform for sharing and reading documents. After reading, relevant articles, citations and bibliographies were organised in Latex using 'Bibtex' (http://www.bibtex.org/) for referencing. The literature included in the research were peer reviewed journal publications as well as documents from grey literature judged as authoritative sources by the researcher.

2.2 An overview of ARC in New Zealand

2.2.1 Residential care in the twentieth century.

Before old-age pensions were introduced in the 19th century in New Zealand, elderly people who became ill or unable to work relied on family support or charity. Institutional support changed between 1908 to 1948, when the larger public hospitals took responsibility for supporting older people (Jefferys, 1989). Furthermore, those who could no longer work or live independently often became residents of benevolent institutions set up from the 1860s by provincial charitable aid boards and religious institutions (Tennant, 1983).

In the mid-20th century the majority of older people had families, but familial dependence was not popular, which again resulted in high residential care entry. During this period social policy moved away from income maintenance, such as age benefits, to social service provision, with the Government subsidising service provision by the establishment of the supplementary assistance program between 1951and 1961. This program not only took into account a person's ability to contribute to the cost of their care, but also that of their family members i.e. income and assets were tested before financial assistance was made available. Additionally, the Rest Home Subsidy Scheme was established in 1961 in the Auckland Hospital area with the aim of

freeing up much needed public hospital beds occupied by elderly long-term patients needing supervisory care, as opposed to specialised care provided by hospitals. This was to ensure that the care of these people would be more appropriately met in rest homes.

During this period charitable organisations began providing both institutional and community services. They received government support for both service provisions and also capital development through the Capital Subsidy Scheme (Koopman-Boyden, 1993). In July 1962 approval was given for the Rest Home Subsidy Scheme to be extended and from 1966 it was progressively introduced around New Zealand with the condition that income and asset test must be carried out. The Geriatric Hospital Special Assistance Scheme (GHSAS) was introduced for long-term nursing care needs, subject to means testing in 1975. Old People's Homes Regulations were introduced in 1987 and included regulating staffing levels and room sizes. With the growth of the profit-making private sector, the Rest Home Subsidy Scheme was extended to religious and welfare homes following a review of the scheme in 1989. The Capital Subsidy Scheme was abolished.

2.2.2 Health restructuring and its impact on ARC.

The health reforms of 1993 saw the restructuring of the hospitals into business units and separate funding arms led to the enactment of the 1993 Universal Income and asset test (Ashton, 2000). The test treats all older people requiring long term residential care in the same way, irrespective of whether they receive that care in a public or private rest home or geriatric hospital. Responsibility for aged care devolved from the Department of Social Welfare to four Regional Health Authorities, which undertook needs assessment and procurement of services. Distinct regional approaches emerged including care categories and prices. In 1994 the Government announced that a maximum amount per week would be payable by people requiring long term residential care. Those who are eligible for a Residential Care Subsidy would contribute their New Zealand Superannuation less a weekly personal allowance, with any excess to be paid by the health authority. In 1995 the Government announced further changes to the income and asset test. These included a provision to financially recognise care given by a non-core family member prior to the older person entering residential care. In 1998 the Health Funding Authority (HFA) assumed in full responsibility for aged care from Regional Health Authorities while Aged-Related Residential Care (ARRC) and Aged Residential Hospital Specialised Services Agreement (ARHSS) national agreements were introduced, with four care categories and prices, and a pricing structure introduced in 2001. These agreements negotiated annually between DHBs and providers, stipulate the scope, specifications and terms

and conditions of ARRC services purchased by DHBs. The scope of services under the ARRC agreements includes: accommodation, needs assessment, care planning and care delivery (including, now, the use of interRAI assessment tools), minimum staffing levels (related to site management and care staff), food and laundry services, amenities and equipment, and access to a range of primary medical services and pharmacy, day activities, as well as quality and risk management obligations.

The evolution of ARC policy continued when in 2003 the responsibility for aged care devolved to DHBs from the HFA, with the expectation that DHBs maintain the national contracting approach for ARC. Policy changes since 1 July 2012 resulted in the asset threshold to qualify for a Residential Home Services (RHS) retained and increased by CPI on 1 July each year. The interRAI Long-Term Care Facility (LTCF) assessment was introduced as the mandatory resident assessment tool sector-wide in 2015.

2.2.3 Assessment and referral to ARC.

To participate in the DHB funded ARC, an individual over 65 years must be needs assessed having high, or very high-needs which are indefinite; unable to be safely supported within the community; and eligible for publicly-funded health and disability services. The four categories broadly encompass the following levels of need:

1. Rest home care; an individual is assessed as generally able to be independent (are mobile and can feed themselves), but needing assistance with personal care or supervision of activities of daily living or unable to safely live in the community.
2. Hospital level care: an individual is assessed as having significant disability, usually in combination with medical problems, which requires 24-hour supervision with Registered Nurse.
3. Dementia care: an individual is assessed as needing 24-hour supervision, in a secure environment due to risk of wandering or becoming lost due to memory loss or confusion.
4. Psychogeriatric care: an individual is assessed as needing 24-hour supervision and high level of specialist nursing care.

Under the Residential Care and Disability Support Services Act 2018, people entering ARC are means tested to assess the level of contribution required.

New Zealand's aged residential care sector has transformed since the government's nationwide funding model was put in place over 20 years ago. In 2017 the Ministry of Health and the 20 District Health Boards commissioned a Review of the Aged Care Funding Model from Ernst and Young (EY), to see how well the model was working and whether it was sustainable for the future. The review made seven primary recommendations, including use of a new funding model more directly linked to individual needs. The recommended funding model would be based on the interRAI clinical assessment approach now used to support the development of care plans in aged care residential facilities (Ministry of Health, 2019).

2.2.4 The transition to ARC.

Residential care for older people is available in most of the developed countries (e.g. nursing homes and hostels in Australia; chronic care or rehabilitation hospitals, and extended care facilities or nursing homes in Canada and the United States; long-term geriatric hospitals and nursing homes in England and Sweden; speciality hospitals, nursing homes and old age homes in Germany) (Abrams, Beers, & Berkow, 1995).

Transition to ARC can be an emotional and stressful event for older people as well as their families and carers (Ellis, 2010), especially as relocation in later life has been said to precede depression, increasing dependence and dislocation from friends and family (Lee, Woo, & Mackenzie, 2002; Milligan, 2004). In a recent study, it has been reported that for many older adults, a lack of control over their lives and loss of independence are the inevitable (or perceived) consequence of ageing and of moving into an aged care facility (Brownie, Horstmanshof, & Garbutt, 2014). Residential care has been the choice of some older people as the safe haven that is required for their abilities and disabilities (Miller & Weissert, 2000). It has given their primary informal caregivers some respite from the continuous and often arduous tasks of the 24-hour support of highly dependent older people in New Zealand (Milligan, 2004) and elderly people who are lonely at home find they enjoy the increased social contact that residential care provides (Mirotznik & Kamp, 2000).

Despite some negative findings from earlier studies, some recent studies have reported that transitioning to an environment that is considered safe and supportive are connected to the feelings of well-being, recovery and healing. A meta-synthesis study that investigated the meaning of home for older adults transitioning into ARC, suggested that when older adults are considering entering ARC, they see an image of health and recuperation and a therapeutic environment that would maintain boundaries, facilitate meaningful engagement, sustain

important relationships, and continue or create routines and rituals (Molony et al., 2010). Additionally, in a recent study that explored Iranian older people's experiences of the transition to an aged care home, it was found that the decision to move into ARC was a positive response in the aftermath of a physical crisis such as having a fall, or experiencing progressive chronic disease, and requiring extensive physical care (Vahid, Vahid, Azad, Lynnette, & Eesa, 2016).

2.3 COPD and functional decline

COPD is a heterogeneous inflammatory lung disease characterised by progressive airway obstruction, which results in exertional dyspnea and physical disability (Goto, 2017). The symptoms of COPD often interfere with many aspects of daily living and are characterised by chronic pulmonary manifestations that greatly impact on the health of an elderly including, functional impairment, quality of life, and a requirement for prolonged assistance or dependence on others for performing activities of daily living (Rodrigues et al., 2015). Furthermore, other studies have found that the presence of COPD is often accompanied by other manifestations including cardiovascular disease, skeletal muscle wasting, cachexia, and normocytic anaemia (Divo et al., 2012; Decramer & Janssens, 2013).

In contrast to the manifestation of COPD and associated co-morbidities, functional decline represents the loss of physical abilities (Clegg et al., 2013) and it is associated with loss of independence, and ultimately death (Fried, 2001). Those with COPD may experience progressive dyspnea and exercise intolerance which limits their ability to carry out ADL (Ries et al., 2007; Pauwels et al., 2001). ADLs are simple activities that are essential for an independent life that includes self-care (showering, dressing, grooming) and basic mobility. COPD may also contribute to undermining IADL, more complex activities that require higher functioning such as preparing meals, handling finances, home maintenance, shopping and travelling alone (Janaudis-Ferreira et al., 2014).

COPD is closely associated with functional decline, with shared risk factors such as ageing and smoking and common mechanisms of deregulated inflammation and endocrine dysfunction (Fragoso et al., 2012; Lahousse et al., 2015). Disability among individuals, especially the elderly, who have COPD is much more pronounced than those without COPD due to functional decline. They have more difficulty in managing money, doing household chores, preparing their own meals, feeding, and dressing themselves, and they require higher levels of health care and support (Park et al., 2013). Such disability can cause severe anxiety and depression (Stuart

et al., 2011), which can subsequently cause a reduction or decline in their ADL and affect their health-related quality of life (HRQOL) (Goto et al, 2004).

In a Dutch study aimed at assessing the occurrence and risk factors of chronic diseases and disability in the elderly, it was found that participants with COPD were more than twice as likely to experience functional decline when adjusted for age, sex, smoking, and co-morbidities. There was also a stronger association among COPD participants with severe airflow limitation, with frequent exacerbation and with more symptoms. The results further suggested that with increasing COPD severity of airflow limitation, the situation for the more intermediate functionally declined elderly deteriorated further (Lahousse et al., 2015).

As life expectancy increases, the quality of those additional years can vary significantly from person to person due to chronic conditions such as COPD, and at some point the elderly will experience functional decline that would hinder independent living and require long-term services and supports. The risk factors for long term care services or residential care entry are discussed in the following section.

2.4 Functional decline and associated factors for ARC entry

2.4.1 Significance of risk factors for ARC entry.

In 1973 Anderson and Newman first used the words ‘predisposing’, ‘enabling’ and ‘need’ factors, as a way of clarifying and dividing the risk factors for the older person entering residential care (Miller & Weissert, 2000). Predisposing factors have been described as characteristics which are usually exogenous to individuals and include demographic, social support and health belief indicators. Enabling factors affecting the decision include indicators of familial and community resources. Need factors identify the older person’s vulnerability (such as having dementia), which could be addressed by residential care entry.

Risk factors for residential care entry can be any serious physical, cognitive or psychiatric disability, but equally important is the lack of services available in the home (Jorgenson, 2007). There has been extensive research on the risk of entry to residential care and the factors that are involved in the entry. A study from the United States provided a substantial literature review of articles written between 1985 and 1998 that form a "prediction" list (Miller & Weissert, 2000). Others have subsequently reported major findings which contribute to the overall

knowledge of factors involved in residential care in countries such as Britain, America and Australia, but there are few articles that refer particularly to New Zealand.

In a 10-year follow up study that investigated the predictors of functions among older adults in the United States, it was found that among 297 survivors from the community, there was little or no decline in social and economic function and only moderate decline in mental, physical, and activities of daily living function. Additionally, it was reported that demographic and socioeconomic characteristics were usually strong predictors of decline in function and impairments in one type of function often predicted greater decline in other types of function (Palmore, Nowlin, & Wang, 1985). Coehn, Eilen and Wallack (1986) estimated the relative importance of the characteristics of community-dwelling older adults for ARC entry using a predictive model, also in the United States. It was reported that age, being confined to a bed, being widowed, never married, and perceived health status were the statistically significant predictors.

A study that investigated transitions between community and ARC in an urban elderly population over the course of a three year observation period, Kelman and Thomas (1990) found that 6% of a representative community residing urban elderly population were admitted to ARC in the United States. Nearly half of this group were still living in ARC at the end of this observation period. One third had died after entering, and the remaining people had returned to their own homes in the community. The authors reported that those who remained permanently in ARC tend to be older and more functionally and mentally impaired. A state-wide probability sample of 1,625 Massachusetts elderly was studied prospectively over a decade to identify risk profiles for long-term care (LTC) institutionalisation. Previous admission to a LTC institution, age, basic ADL disability, and restricted outside mobility were the strongest individual predictors of institutionalisation (Jette, Branch, Sleeper, Feldman, & Sullivan, 1992). It was concluded that examining profiles of risk factors dramatically increased the ability to predict 10- year risk of admission.

Temkin-Greener and Meiners (1995) examined transitions between the community and ARC among older persons in the United States. They used estimations from a discrete-time hazard functions to determine factors associated with the probability of these transitions. The analysis showed that recent hospitalisations for stroke, dementia, or hip fractures, while strongly predictive of ARC admissions. A study by Van Rensbergen and Pacolet (2012), that

investigated factors that trigger urgent request for ARC entry among a cohort of 125 elderly who were admitted to four residential care in Antwerp (Belgium), found that decline in physical functional capacity in advanced activity of daily living was the risk factor that caused these elderly to be admitted.

An early study in New Zealand to determine if Assessment Treatment and Rehabilitation Units (ATR) assessment was necessary prior to residential care admission did not determine the entry factors (Wilkinson & Sainsbury, 1992). However, a subsequent New Zealand study in 2004 examined the NASC referrals to ascertain which people were referred to residential care and the factors that made this entry possible. The authors used retrospective administrative data of people aged 65 years and above who had this assessment to predict the relative risk of residential care entry as well as the factors contributing to this risk. Of those assessed, it was found that continence problems, mobility problems and dementia predicted residential care entry (Weatherall, Slow, & Wiltshire, 2004).

2.4.2 Activities of Daily Living: indicator of ARC entry.

Measures of functional disability typically contain items that reflect limitations in performing ADLs or IADLs (Spector & Fleishman, 1998). One of the main criteria used in ARC entry pre-admission assessments in many countries is limitations in ADL (Fong, Mitchell, & Koh, 2014) and a principal goal of the care of older patients is maintaining the ability to perform basic self-care activities (Covinsky et al., 2003). ADLs, or basic ADLs, include the fundamental skills typically needed to manage basic physical needs. These comprise the following: grooming/personal hygiene, dressing, toileting/continence, transferring/ambulating, and eating. ADLs comprise different types of skills requiring sequencing of action, conceptual knowledge, and manipulation needed to achieve the intended goal (Bie, Brandi, Goldenberg, Hughes, & Hermsrfer, 2014). Basic ADLs are generally categorised separately from IADLs, which include more complex activities related to independent living in the community (e.g., managing finances and medications) (Mlinac & Feng, 2016b).

The International Classification of Functioning, Disability and Health (ICF), established a consensus in its understanding, by establishing a difference between the basic ADL and the IADL (World Health Organization and others, 2001). The ADLs as outlined above, are essential and routine chores that individuals can achieve without the need for assistance. They are central to the ability to comprehend the experience of the elderly who transitioned into residential care (Ikegami, Morris, & Fries, 1997; Phillips et al., 1997). IADL, on the other hand

are more complex, require higher level of personal autonomy and enough capacity to make decisions and manage greater interaction with the environment. In the 1960s, Lawton and Brody (1969) were amongst the first to assess IADLs and their impact on the ability of older people to live in the community independently. They reported that that assessment of older people is a complex process requiring evaluation from different vantage points. The Lawton's Instrumental Activities of Daily Living (IADL) Scale was developed to assess more complex activities necessary for functioning in community settings (financial and medication management, driving, shopping, house cleaning, and meal preparation). IADL dependencies reflect higher order functional impairments due to the cognitive demands required for successful task completion (Gold, 2012).

ADL dependence is correlated with poorer quality of life. A Spanish study aimed to establish the existing relationship among variables that characterise 598 individuals older than 65 years and the functional dependence in basic ADL and in IADL, as well as the possible relationship these have with the increase of morbidity and mortality. It was found that 34.6% of people were dependent for at least one ADL, and 53.5% are in IADL. Additionally, regarding ADL, the risk of dependence increases with age (Millán-Calenti et al., 2010). Changes in ADL lead to institutionalisation or ARC entry. A retrospective 1-year cohort study using national data of 22,557 older adults who consistently received either ARC care (n =11,678) or home care (n = 10,879) was conducted in Korea (Lee et al., 2015). The aim of the study was to compare the level of ADL risk between community dwelling older adults and those who have already transitioned into ARC. Multiple regression analysis of all participants unmatched and a paired t-test with a propensity-score-matched cohort were performed to explain the association of changes in ADLs with the types of care. The result showed that compared with older adults who received home care, those who received aged residential care had deteriorated further in terms of ADLs after one year. After propensity-score matching, paired t-test analysis also found that the ADLs of older adults had deteriorated less in the home care group compared with the nursing home group after 1-year (Lee et al., 2015).

Additional studies have demonstrated that knowing a person's total number of ADL limitations can help predict the chances of community-dwelling adults subsequently entering aged residential care. Salive et al. (1993) found that the risk of institutionalisation increased five-fold for elderly persons with 3 or more ADL limitations, but only twofold for those with 1-2 limitations in a biracial North Carolina cohort in the United States. Furthermore, in a meta-

analysis of studies investigating the risk of ARC entry in the United States, it was reported that the risk of subsequent ARC entry increased substantially for older adults having 3 or more ADL dependencies. As a result the level of functional impairment based on ADL was one of the strongest predictors of ARC entry compared to other commonly used socioeconomic control factors (Gaugler et al., 2007).

2.4.3 Ethnicity: an indicator of ARC entry.

Many studies have mentioned significantly lower rates of residential care entry based on ethnic background. Miller and Weissert (2000) in the systematic review conducted in the United States found that in 29 out of 33 studies, being "non-white" decreased the chances of institutionalisation. Furthermore, in another US study, of 4,646 participants in a day program for seniors age 55 and older, researchers examined the predictors of ARC entry occurring within 3 years, and found that among these community-dwelling seniors, advanced age and identifying as "white" were associated with greater likelihood of institutional living (Friedman, Steinwachs, Rathouz, Burton, & Mukamel, 2005).

Among the "non-white" group, the majority of older people needing care remain in the community and are cared for by family and friends. However, the extent to which family and friends provide assistance varies across ethnic groups, reflecting both cultural and socio-economic differences. Cultural explanations for the differences have emphasised consumers' attitudes, backgrounds, beliefs, and behaviours (Pandya, 2005). Black, Rabins and German (1999) as well as Kersting (2001) in their research found out that being of European descent ("white") was a risk factor for residential care entry. In another finding, people of European background were 66 percent more likely to be institutionalised than people of non-European background (Bauer, 1996; Palmore, 1976).

In the last decade, more recent findings have found that ethnicity is significant in deciding who get admitted into ARC. A study using the data from the Health and Retirement Study (HRS) (1998-2010), a nationally representative biennial survey of persons over the age of 50, investigated health and disability-based factors relate to ARC admission among three different ethnic groups in the United States. The study found that Hispanics have a 34% lower risk of entering ARC during the study period compared with non-Hispanic white adults and that Non-Hispanic black and non-Hispanic white respondents have statistically similar risks of ARC admission (Thomeer, Mudrazija, & Angel, 2014).

In New Zealand, it has been argued that for Māori the concept of ageing and staying within the community is considered a deep spiritual act which cannot be exercised if they transitioned to some ARC facility. This is about a connection to the land and a sense of contributing to something beyond the self, of giving for a common purpose in passing something on and in the readiness for leaving something behind (Wright St Clair, 2009). Also, within many Pacific traditions the central purpose of elders' lives includes their ability to act as guardians and pass on their heritage to their descendants, hence the need live in close proximity to their children and grandchildren (Tamasese, Parsons, & Waldegrave, 2014).

Recent evidence shows that the differences between ethnic groups in New Zealand may reflect different ways of caring for older people. According to Statistics New Zealand (2015), older people who moved into residential care were of European ethnicity. Conversely, the Māori, Pacific peoples, and Asian ethnic groups had lower proportions moving into ARC.

2.4.4 Loneliness: an indicator of ARC entry.

Loneliness has been defined as a subjective, distressing feeling which has been shown to be associated with decreased quality of life and impaired health (Savikko et al., 2008). It is an important contributor to human suffering, especially in elderly persons, among whom prevalence rates may be high (Ekwall, Sivberg, & Hallberg, 2005). Some studies have suggested that loneliness is distinct from several quantitative measures of social isolation such as living alone, marital status, and number of relationships. Perissinotto, Cenzer and Covinsky (2012) argued that it is possible for persons who live alone to not feel lonely, while some who are married or living with others will still experience loneliness.

Among older community-dwelling populations, its prevalence varies. About 20% to 40% of older people in the United States report feeling lonely (Luo, Hawk- ley, Waite, & Cacioppo, 2012), with 5% to 9% of people in Ireland reporting feelings of intensive or painful loneliness (Golden et al., 2009). Also, comparative data from a survey of a national representative sample conducted by the American Association of Retired Persons (AARP; n = 3,012) estimated that 25% of community-dwelling US respondents over the age of 70 years were lonely, as measured by a score of 44 or higher on the 20-item UCLA Loneliness Scale (Wilson & Moulton,2010). In New Zealand, recent research indicates that about half of older New Zealanders experience some level of loneliness, and 8-9% feel lonely all or most of the time, and that it is common for older people who had interRAI-HC assessment to be lonely, with patterns of loneliness relating to other factors (Jamieson et al., 2018).

Across the world, studies of the risk of ARC entry because of loneliness have contributed to a growing body of evidence. In China, among community-dwelling elderly, a sudden loss of a close acquaintance, or the loss of the primary support person results in loneliness (Lee, Woo, & Mackenzie, 2002). Similarly, Tomiak, Berthelot, Guimond and Mustard (2000) in Canada reported loneliness to be very common and higher among men who lose a partner.

Many studies concur that loneliness is a risk for admission to residential care. Hence, loneliness results in the need for the return of security of support and is seen as predictive factor for residential care entry (Jörgensen, 2006). Additionally, with regard to residential care entry through loneliness, in a study conducted among the elderly who live in rural Iowa, higher levels of loneliness were found to increase the likelihood of ARC admission (Russell, Cutrona, De la Mora, & Wallace, 1997). Russell (1997) reported the death of a spouse is the most potent predictor of loneliness among older people.

As discussed in chapter one of this thesis, functional decline or poor health status (such as the presence of chronic conditions) among the elderly leads to ARC entry. Loneliness is also a risk factor for poor health outcomes including death and multiple measures of functional decline (Perissinotto et al., 2012). The decline as a result of loneliness may have serious effect on other areas of health and lifestyle. Those who are lonely have worse sleep and poor health behaviours (including poor medication adherence), suggesting that these behaviours may account for their poor health outcomes (Shankar, McMunn, Banks, & Steptoe, 2011; Hawkley & Cacioppo, 2007). Among community-dwelling older persons, both feeling alone and being alone are associated with more rapid motor decline, underscoring the importance of psychosocial factors and motor decline in old age (Buchman et al., 2010). Buchman et al (2010), assessed loneliness with a 5-item scale in 985 persons without dementia participating in the Rush Memory and Aging Project, a longitudinal community-based cohort study in the US. Results further showed that after adjusting for age, sex and education using a linear mixed-effects models, the level of loneliness was associated with the rate of motor decline. The association between loneliness and motor decline persisted even after controlling for depressive symptoms, cognition, physical and cognitive activities, chronic conditions, as well as baseline disability or a history of stroke or Parkinson's disease.

2.4.5 History of falls: an indicator of ARC entry.

A fall is defined as an event which results in a person coming to rest inadvertently on the ground, floor or other lower level. Fall-related injuries may be fatal or non-fatal and though

most are non-fatal, falls are the second leading cause of accidental or unintentional injury deaths worldwide (World Health Organisation, 2012). The WHO estimates that the financial costs from fall-related injuries are substantial. For people aged 65 years or older, the average health system cost per fall injury in Finland and Australia were $3611 and $1049 respectively (World Health Organisation, 2012). Falls have been found to limit daily activities and induce post-fall syndromes, such as dependence, loss of autonomy, immobilisation, and depression (Centre for Health Promotion, Public Health, and Unit BCIRPU Prevention, 2012; Park, 2018).

Falls can occur as a result of any combination of intrinsic, extrinsic, or behavioural factors. Intrinsic factors are due to age and/or disease-related changes within older adults that increase the probability of falling. Intrinsic risk factors can include medications, visual impairments, postural instability, weakness, and a decline in cognitive function. Extrinsic factors include environmental hazards that produce the opportunity for a fall to occur, such as tripping over an uneven surface (Greany & Di Fabio, 2010). Behavioural factors are specific activities that people engage in that may contribute to risk of falling, such as climbing a ladder (Lach et al., 1991).

Falls have been shown to result in a decline in function as a result both of physical injury and of a loss of confidence with regard to the ability to perform functional activities (Tinetti, De Leon, Doucette, & Baker, 1994; Tinetti & Williams, 1997). The Centre for Disease Control estimated that in the United States, almost 25 percent of persons who fall have moderate to severe injuries, ranging from bruises or lacerations to hip fractures or traumatic brain injury, resulting in more than 1.9 million emergency department visits annually (Centers for Disease Control and Prevention, 2016). Injuries, such as hip fracture, and falls are risk factors for entry into a residential care (Tinetti & Williams, 1997) where the fall risk is nearly three times that of persons living in the community (Rubenstein, Josephson, & Robbins, 1994).

The burden of falls on older people is enormous as they have an increased susceptibility to injury due to the higher prevalence of co-morbidities, age-related physiological changes, and delayed functional recovery, which in turn lead to further de-conditioning and more falls (Rubenstein & Josephson, 2002). About 30-50% of falls result in minor lesions such as bruises or lacerations, however, 5-10% of falls lead to major injuries such as fractures (Goldacre, Roberts, & Yeates, 2002) or traumatic brain injury (TBI) (Rubenstein & Josephson, 2002). Falls are the most common cause of TBI in older adults, and also account for 46% of all fall

related deaths in TBI patients according to the CDC (Centers for Disease Control and Prevention, 2016). Although the rate of hip fractures following a fall is only 1%, 90% of all hip fractures are caused by a fall (Goldacre et al., 2002). In the first year following a hip fracture, 25% of older patients will die (Abdelhafiz & Austin, 2003), 76% will have a decline in their mobility(March et al., 1999), 50% will have a decline in their ability to perform ADL (Abdelhafiz & Austin, 2003) and 22% will move into an aged residential care or nursing home (March et al., 1999).

Falls are common among the elderly and have been indicated as a common reason for ARC entry. In the late twentieth century, Tinetti and Williams (1997; 1988) argued that non-fatal falls are the most frequent cause of injury-related morbidity in this age group and those who experience one non-injurious fall have 3.1 times the risk of admission to a long-term care facility compared to those with no fall history. This outcome was from a study that investigated the effects of falls and fall injuries on functioning in community dwelling older persons in the United States who were followed for a period of three years. They also reported one non-injurious fall, at least two non-injurious falls and at least one injurious fall were each associated with decline in Basic ADL-IADL function over 3 years after adjusting for covariates. Furthermore, experiencing two or more non-injurious falls was associated with decline in social activities while experiencing at least one injurious fall was associated with decline in physical activity.

A fall, as an adverse event in combination with other risk factors, influences ARC placement. A retrospective longitudinal study of 6,515 high-risk, community-dwelling participants in a waiver program during 2002-2007 were examined by Spoelstra, Given, You and Given (2012). They obtained data from the Minimum Data Set-Home Care linked with Medicaid claim files and fitted multiple factors to a logistic curve, using generalised linear modelling to predict increased risk of ARC placement when a fall occurred. The result showed that an increased rate of falls and increased ARC placement and concluded from the research that an adverse event such as a fall is a strong predictor of ARC placement and should be taken into consideration while developing care plans for community-dwelling older adults.

A study that investigated interventions for preventing falls for community-dwelling older people in the United States, using a randomised trials of interventions, found that group and home-based exercise programmes, and home safety interventions reduced the rate of falls and

risk of falling among adults older than 65 years of age. Those older adults who did not respond to these fall interventions suffer the greatest number of fatal falls and were at greater risk of being institutionalised (Gillespie et al., 2012).

In a twelve month prospective cohort study, Laird, Studenski, Perera and Wallace (2001) investigated whether a history of falls predicted functional decline and adverse outcomes such as hospitalisation or ARC entry. The authors reported that among members of a Medicare managed care program, at baseline, 70% reported no falls, 18% had one fall, and 12% reported two or more falls. Fall status predicted functional decline. Fall frequency was a univariate predictor of adverse outcomes (hospitalisations, nursing home placement, or death) and of hospital utilisation alone. One or more adverse outcomes occurred in 18% of those who reported no falls, 22% of those who reported one fall, and 38% of those who reported two or more falls. Following adjustment for likelihood of future adverse outcomes, these associations remained predictive for higher number of reported history of falls. They concluded that fall history predicts decline in function, hospitalisation, and ARC entry among a Medicare managed care population and remains independently predictive of poor outcomes after controlling for baseline function and likelihood of future adverse outcomes.

2.4.6 Pain: an indicator of ARC entry.

In recent times, the concept of pain has evolved from a one dimensional to a multi-dimensional entity involving sensory, cognitive, motivational, and affective qualities, controlled by many factors (Kumar & Elavarasi, 2016). The North American Nursing Diagnosis Association defines pain as a state in which an individual experiences and reports severe discomfort or an uncomfortable sensation; the reporting of pain may be either by direct verbal communication or by encoded descriptors (Keane & O'Toole, 2003). Pain is common in the advanced stages of many chronic diseases, including congestive heart failure, end stage renal disease, and COPD (Smith et al., 2010). In the United Kingdom, it is highly prevalent among older people living in the community, with estimates for current pain of 20% to 46% and for chronic pain ranging from 25% to 76% (Abdulla et al., 2013).

A significant proportion of the elderly are affected by chronic pain, resulting in a decreased quality of life and the use multicomponent strategies to find the most effective and safest combinations of pain medications to achieve adequate pain control is required (Murphy, Karlin-Zysman, & Anandan, 2018). Similarly, in a recent US study that examined the epidemiology, risk factors, and treatment for the prevention of chronic pain using preventive strategies models,

it was found that chronic pain among community-dwelling older adults is a risk factor for worsening frailty and eventual institutionalisation (McGreevy, Bottros, & Raja, 2011).

Pain plays a significant role in the lives of older adults. Almost twenty-five percent of community-dwelling older adults report pain that interferes with normal function, and half of those already in residential care have reported daily pain with an inevitable impact on the quality of life and functional capacity (Hall, 2016). Hall (2016) also reported the challenges at managing this pain including: the myth that experiencing pain is natural with increasing age, co-morbidities that affect pain, lack of congruence between patients' and caregivers' perceptions of pain; under reporting and perceived reliability of reported pain; sensory and cognitive impairment; fears of addiction to analgesics; risks and fears of polypharmacy, and caregivers' belief systems. The myth that experiencing pain is natural with increasing age was found in a study conducted among the elderly in Australia. The study concluded that patients strongly endorse the belief that persistent pain is a normal part of ageing and there is little potential for improvement (Weiner & Rudy, 2002).

Among New Zealand interRAI studies recently published, one investigated the prevalence of pain and its relationship to other risk factors in a cohort of older people living in the community. It was reported from this study that the rates of severe daily pain were 12%-18%, with those in the 65-74 years group having the highest reported rate of severe pain (18%) and a gradual decrease in severe pain with age (Crowe et al., 2017). However, there are no published regarding the experience of pain in older persons entering aged residential care in New Zealand.

2.4.7 Age: an indicator of ARC entry.

Age has consistently be shown as one of the predictors of entry to aged residential care (Miller & Weissert, 2000). In a recent prospective cohort longitudinal study that investigated the health, social and lifestyle factors for entry to residential care in Australia, it was reported that the likelihood of entry to residential care increased by more than 15% for every additional year of age, everything else being equal (Kendig, Browning, Pedlow, Wells, & Thomas, 2010). In New Zealand, the Ministry of Health (MOH) reported in 2001 that the proportion of older adults that transitioned to ARC increased with age, upward from 1.3% for those aged between 65-74 years, 5.7% for the those between 75 and 84 years and at a significantly high rate of 24.5% for all those above 85years (Dyson,2002).

However, the notion that older adults are always at risk of ARC entry may not be sufficient enough in itself, as found in an older study by Shapiro and Tate (1988) conducted in Canada. They argued that older adults within the age group of 65-84 and with less than 3 ADL related issues were less likely to move into a residential care. Additionally, an early New Zealand study of 200 older people in institutional care did not consider age or co-morbidity to be predictive factors (Wilkinson & Sainsbury, 1992).

2.4.8 Cognition: an indicator of ARC entry.

The effect of cognitive impairment increases with age and, among many older persons above the age of 65 years, this may be as simple as difficulty recalling a person's name or where they went (Brookmeyer et al., 2011; Royall, Palmer, Chiodo, & Polk, 2005; Wang et al., 2011).

Within the community setting, many scales and scores have been developed to measure the loss of cognition (Wright, Bushnik, & O'Hare, 2000) such as the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) and the Cognitive Performance Scale (CPS). The CPS scale combines information mainly on a person's ability to make daily decisions, their ability to make themselves understood, and their memory impairment. CPS scores range from 0 (intact) to 6 (very severe impairment).

Several studies have examined the use of cognition in predicting outcomes such as institutionalisation and mortality. In a study predicting ARC entry using the Minimum Data Set in the United States, it was found that higher cognition values at the point of entry to residential care predicted earlier mortality, controlling for other factors such as demographics, physical functioning, and frailty (Lee, Chau, Hui, Chan, & Woo, 2009). Additionally, in a study that investigated survival after multiple hospitalisations for infections and dehydration in nursing home residents with advanced cognitive impairment, poor survival among residents with cognition values between 4 and 6 was found (Teno, Gozalo, Mitchell, Tyler, & Mor, 2013).

Gnjidic et al (2012) investigated the evidence of the contribution of cognitive impairment to institutionalisation in older adults. The study aimed to evaluate a range of risk factors including cognitive impairment especially in older men. Men aged ≥70 years (n=1705), participating in the Concord Health and Ageing in Men Project, Sydney, Australia were studied. Participants completed self-reported questionnaires and underwent comprehensive

clinical assessments during 2005–2007. Cox regression analysis was conducted. The authors reported that a total of 125 (7.3%) participants were institutionalised and cognitive impairment predicted institutionalisation in the period beyond 3.4 years of follow-up. Community-dwelling older adults who have no cognitive impairments may have different outcomes. A five-year, longitudinal follow-up study of all persons 65 years and older in Canada was conducted by Tuokko et al (2003). The aim was to investigate outcomes for persons with no cognitive impairment or cognitive impairment but no dementia. They found that 29% of people with cognitive impairment but no dementia at follow up were institutionalised, whereas 14% of people with no cognitive impairment at follow up were institutionalised. The risk of institutionalisation or ARC entry was twice for those who have cognitive impairment compared with those who did not. They also reported that persons with cognitive impairment but no dementia were more likely than those with no cognitive impairment to die (49% vs 30%), or to receive diagnoses of dementia (47% vs 15%) at follow-up.

Pooled logistic regression was used to determine whether an older person was at risk for ARC admission or not at some point in the future (Gaugler, Duval, Anderson, & Kane, 2007). The study conducted in the United States found that elderly persons with 4 or more errors on a short screening tool, the Short Portable Mental Status Questionnaire had more than twice the odds of entering ARC within three years. The authors concluded that indicators of functional and cognitive impairment were among the strongest predictors of admission such that the presence of cognitive impairment, assessed through either proxy/other subjective measures or four or more errors on clinically validated short screening tools were found to be strongly linked to subsequent residential care entry (Gaugler et al., 2007).

2.4.9 Hospitalisation: an indicator of ARC entry.

Older adults are considered vulnerable members of society with regard to their health, and the number of hospitalised elderly has been steadily increasing worldwide. Some elderly adults are admitted to hospital with a diagnosis not directly leading to functional deterioration, yet they demonstrate a general decline in function after a hospital stay (Mudge, O'Rourke, & Denaro, 2010). Time spent in the hospital has been reported to be an important risk of residential care entry (Bebbington, Darton, & Netten, 2001; Miller & Weissert, 2000). For example, the longitudinal study by Bebbington, Darton and Netton (2001) focused on the characteristics of newly admitted long-stay publicly-funded residents, and their outcomes and costs over the following three and half years among 2500 residents in the United Kingdom. Information was collected on their personal characteristics, health and dependency at the time

of admission, circumstances prior to admission, subsequent moves and survival, and health and dependency at 6, 18, 30 and 42 months after admission. They reported that over one half of all people were admitted direct from a hospital. Four-fifths of these were known to have been there for less than eight weeks. They concluded that the point of hospital stay was commonest time of entry following a health event requiring hospitalisation, such that a return to the former private household was not practicable. Adverse health outcomes are sentinel events for many older persons that may mark a transition from independent living to either community-based or institutionalised long-term care (Rudberg, Sager, & Zhang, 1996; Sager et al., 1996).

An acute hospital admission may occur in response to an acute illness, as a complication or progression of a chronic health condition or a deterioration in an individual's social circumstances requiring urgent help (Harrison et al., 2017; Sager et al., 1996). In the United Kingdom, Dwyer (2005) found that about 43 percent of elderly who received lower level support and 63 percent who received higher level support after being in hospital transitioned into residential care. The aggravation of the causes of hospital visits and admissions among older adults are reasons why they can no longer maintain their independence, as found in a study in Australia (Cheek & Ballantyne, 2001). In a study that investigated minimising the effect of hospitalisation on older adults in Israel based on various comprehensive geriatric assessments, the research found that physical recuperation of older adults is more difficult and requires longer hospital stays, hence they often need to be discharged to nursing homes because of decreased functioning and the need for help (Admi, Shadmi, Baruch, & Zisberg, 2015).

2.4.10 Urinary Incontinence: an indicator of ARC entry.

Urinary Incontinence (UI) is an involuntary loss or leakage of urine. Incontinence is usually associated with ageing with approximately 10% of people experiencing urinary incontinence at some point in adulthood, and with incidence increasing with age (Bettez et al., 2012). Furthermore, it is a geriatric syndrome that causes economic and social impacts derived from high treatment costs and caregiver burden, as well as physical consequences for the health of the elderly (Aguilar-Navarro et al., 2012). Within the residential care setting, it is extremely prevalent, affecting more than 50% of all elderly residents (Narayanan, Cerulli, Kahler, & Ouslander, 2007; Leung & Schnelle, 2008). It has been found in 11 to 34% of men and 13 to 50% of women older than 60 years, and in 43 to 80% of all aged residential care residents in the United States (Jerez-Roig, Santos, Souza, Amaral & Lima, 2016; Bedretdinova, Fritel, Panjo, & Ringa, 2016; Markland, Richter, Fwu, Eggers, & Kusek, 2011).

UI significantly decreases quality of life and increases the risk of depression (Aguilar- Navarro et al., 2012; Dugan et al., 2000), disability and social isolation (DuBeau, Simon, & Morris, 2006). Additionally, it is associated with increases in adverse outcomes such as hospitalisation and aged residential care entry (Thom, Haan & Van Den Eeden, 1997; Hsu et al., 2014). Hsu et al (2014) sought to characterise the effect of urinary incontinence among ARC eligible community dwelling frail older adults in the United States who enrolled in the All-inclusive Care for the Elderly (PACE) program between 2004 and 2010. They reported that the inability to ambulate or transfer independently results in high frequency of incontinence putting the cohort at an increased risk of ARC entry.

In Canada, it has been found to be a predictor of nursing home entry (Maxwell et al., 2013) and in the United Kingdom a predictor of long term care entry (Collerton et al., 2009). Maxwell et al (2013) estimated the incidence of ARC placement and identified predictors of placement among 1,086 elderly persons. Predictors of placement were identified with multivariable Cox proportional hazards models. Significantly increased risk for placement was evident for older residents with severe bladder incontinence (frequent bladder incontinence or no control). Collerton et al (2009) studied the clinical, biological, and psychosocial attributes of 1042 cohort of 85 year and above examining their subsequent health trajectories over time. Participants were assessed by nurses at home. They reported severe and profound urinary incontinence in 21.3% of the cohort and were at an increased risk of requiring support and institutionalisation.

A study in New Zealand determined whether urinary incontinence (UI) and faecal incontinence (FI) were independent risk factors for aged residential care admission for older people after controlling for confounders (Schluter, Ward, Arnold, Scrase, & Jamieson, 2017). Those aged 65 years and above with an interRAI-HC assessment between July 1, 2012 and May 31, 2014 were matched to national mortality and ARC databases. Competing risk regression models were applied to those without collection devices or indwelling catheters who were admitted to ARC or alive 30 days and above after their interRAI-HC assessment. The authors reported 36.4% had urinary incontinence with 17.9% of those reporting frequently or completely incontinent. UI was associated with an increased likelihood of ARC admission, with those who experienced incontinence having a SHR 1.11 times that of their continent counterparts, even after adjusting for the suite of demographic and clinical variables. Schluter et al (2017) concluded that the probability of being ARC admission-free decreased as incontinence

frequency increased and that efficacious interventions targeting the management of UI for older people living at home is one lever in reducing New Zealand's increasing ARC demand.

2.4.11 Gender, Relationships and Living Arrangements: indicators of ARC entry.

In a study that investigated the factors associated with residential care entry by focusing on residential pattern of older adults before institutionalisation, Dick, Friedsam and Martin (1964) found that the decision to transition into a residential care was associated with changes in health, family structure changes and gender. Within gender, in a study that investigated socio-demographic variations in moves to institutional care in the United Kingdom, it was found that men are less likely to transition into a residential care than women (Grundy & Jitlal, 2007).

In identifying socioeconomic, health and lifestyle factors of entry to residential aged care facilities in Australia, Kendig et al (2010) conducted a prospective cohort study between 1994 and 2005. One thousand community-dwelling older adults aged 65 years and above were used as baseline sample. Cox regression models identified baseline predictors of subsequent entry to residential aged care for men and women from among socio-demographic, health status and lifestyle factor. At the end of follow up, the proportions of those who had entered residential care were 41% for women and 27% for men including the deceased. The authors reported that the regression estimates showed that for men and not women, having more medical conditions increased the risk of entry to care. Additionally, the study showed that within the gender specific attributes, never being married or widowed was significant for entry to residential aged care mostly for women and they are more likely to experience loss of support at advanced ages leading to an increased risk of ARC entry. They concluded that an understanding of gender specific attributes separately revealed different risk profiles for ARC entry.

When living arrangements are considered, Nihtila and Martikainen (2008) reported from research in Finland that the residential care admission risk is significant among those who were married and for those who live alone, irrespective of gender. This significant difference has been argued to be the result of elderly men being unable to self-care and socio-cultural gender stereotyping (McCann, Donnelly, & O'Reilly, 2012; Doran, Drever, & Whitehead, 2003). Furthermore, it has been reported that, as many women marry men older then themselves, spouses of elderly women tend to develop age-related frailty faster as well as being exposed to increased risk of mortality (Ní Bhrolcháin, 2005). Based on the data from the Northern Ireland Longitudinal Study (NILS) derived from the Northern Ireland Health Card registration system

where 20830 elderly over the age of 65 years were followed for a period of 6 years, McCann, Donelly and O'Reilly (2012) discovered that those who identified as women were 40% more likely to be admitted to ARC than men. It was further reported that, regardless of gender, many elderly were at risk of ARC admission once they start to live alone after the demise of a spouse.

2.5 Prognostic Scores

2.5.1 Background to prognostic modelling.

Prognosis simply means foreseeing, predicting, or estimating the probability or risk of future conditions. In health, prognosis commonly relates to the probability or risk of an individual developing a particular state of health (an outcome) over a specific time, based on his or her clinical and non-clinical profile. Outcomes are often specific events, such as death or complications, but they may also be quantities, such as disease progression, (changes in) pain, or quality of life (Moons, Royston, Vergouwe, Grobbee, & Altman, 2009). Prognostic studies have always focused on analysing important predictors and outcome probabilities for a number of different combinations. These are commonly called prognostic model or risk scores (Steyerberg, Borsboom, van Houwelingen, Eijkemans, & Habbema, 2004). The main objective was to establish the risk of having a change in the health status of an individual and possibly provide a pathway to make an informed decision. They also assist health care professionals in making use of combinations of factors to estimate the absolute risk or the probability of an outcome (Moons et al., 2009).

Before a prognostic model score is used in practice, there must be sufficient evidence to ascertain that it is appropriate and applicable to the current situation. Therefore, evaluation of the model is important. The evaluation could be laboratory based or clinical (Perel, Edwards, Wentz, & Roberts, 2006). Laboratory evaluation is concerned with the statistical performance of the model. Clinical evaluation aims to determine if the model can effectively address a clinical scenario. They authors further argued that for a prognostic model to be clinically useful, it should be clinically valid, methodologically valid and user-friendly, so that applicable conclusions can easily draw to the current situation. They are to make use of large sample sizes in order to achieve accurate measurements and are research-based to establish the relationship between certain clinical characteristics, interventions and likely outcomes.

Prognostic models should reflect clinical credibility and evidence of accuracy, effectiveness and generality. Wyatt, Jeremeny, Alan and Douglas (1995) stated that to ensure clinical credibility, data required should easily be obtainable in a timely manner to make enough prediction, calculations should be simple to allow the generation of prediction and relevant data should have been used for model inclusion testing. They further posited that the accuracy of the prognostic model should also be apparent, and therefore, the model should have a low incidence of false-negative and false-positive results. The generality of the model should be readily discernible such that it can be replicated in another population and in different environment and time. Finally, there should be evidence of clinical effectiveness, perhaps from well-documented clinical trials that exhibit the accuracy of the model (Fine et al., 1995).

The characteristics and qualities of these scores help to identify variables that are needed to predict those at risk. These qualities ensure the internal validity, external validity, reliability and clinical utility of the prognostic scores (Streiner & Norman, 2003). These characteristics represent the comprehensive sampling of the domain interest being captured, the inter-correlation of the items, the consistency with background theory of the domain being investigated, extent to which patients can be distinguished from each other, the extent to which one can assign qualitative meaning to quantitative scores and ability to detect clinically important changes over time (Terwee et al., 2007). Prognostic scores use data that are gathered at population level and individual level. The population level involves recognising trends or outliers in a group using a special criteria while individual level data are used to determine care episodes (Abu-Hanna & Lucas, 2001).

2.5.2 Use of prognostic scores.

Prognostic scores or models are useful in a variety of settings, their use could be based on disease type, patient population or care settings or research type such as randomised clinical trials (Lau, Cloutier-Fisher, Kuziemsky, Black, et al., 2007).

2.5.2.1 Emergency and Acute Care.

Prognostic scores have also be very useful in emergency acute care. The Identification of Seniors at Risk (ISAR) has been developed in Canada to identify elderly patients at risk of functional decline in the Emergency Department (ED). This two-step system includes screening to identify those at risk of adverse outcomes and secondly assessing those with ISAR score of two or more. It was developed from a cohort of 1673 participants (McCusker et al., 1999).

2.5.2.2 Mortality, Hospitalisation and Palliative Care.

A prognostic index for 1-year mortality in older adults (PIMOA) has been developed (Walter et al., 2001). The authors developed and validated a prognostic index for 1-year mortality of older adults after hospital discharge using information readily available at discharge. The data analyses derived from two prospective studies with 1-year of follow-up, conducted in 1993 through 1997. The prognostic index was developed in 1495 patients aged at least 70 years who were discharged from a general medical service at a tertiary care hospital and validated in 1427 patients discharged from a separate community teaching hospital. Walter et al (2001) identified 6 independent risk factors for mortality and weighted using logistic regression: being male, number of dependent ADLs at discharge, congestive heart failure, and cancer, higher levels of creatinine and low albumin level. Risk scores were calculated for patients by adding the points of each independent risk factor present. In the derivation cohort, 1-year mortality was 13% in the lowest- risk group (0-1 point), 20% in the group with 2 or 3 points, and 37% in the group with 4 to 6 points, and 68% in the highest-risk group (>6 points). In the validation cohort, 1-year mortality was 4% in the lowest-risk group, 19% in the group with 2 or 3 points, 34% in the group with 4 to 6 points, and 64% in the highest-risk group. The area under the receiver operating characteristic curve for the point system was 0.75 in the derivation cohort and 0.79 in the validation cohort. The prognostic index is a simple point scoring system that can be used at beside to stratify elderly medical individuals into high, intermediate and low risk groups for mortality during a year following hospital discharge.

Mortality reduction has been found among elderly who suffer from heart failure after admission to hospital using validated point-of care risk prediction score (Eapen et al., 2013). In situations where the risk of mortality cannot be reduced in the face of deteriorating functional, emotional, cognitive and disease status, defined end-of-life care and goals derived from validated predictive scoring system that can be used by clinicians and relatives (Porock et al., 2005).

2.5.2.3 Hospitalisation and Functional Decline.

Inuoye et al (1993) developed and validated a predictive index to identify on admission elderly hospitalised medical patients at risk for functional decline. A group of 188 and 142 hospitalised general medical patients aged ≥70 years were used for the development and validation cohort respectively. A risk-stratification system was developed by adding the numbers of risk factors. Functional decline occurred among 27% of the patients. They found four independent baseline risk factors for functional decline: decubitus ulcer, cognitive impairment, functional impairment and low social activity level. Risk score categories of

functional decline were low (0), intermediate (1–2), and high (3–4). The rate of functional decline based on these risk categories were 8%, 28%, and 63% respectively in the development cohort while corresponding rates in the validation cohort, of whom 24% developed functional decline, were 6%, 29%, and 83%. The risk index further showed rates of death or ARC entry associated with functional decline in the hospital, were 6%, 19%, and 41% in the development cohort and 10%, 32%, and 67% in the validation cohort, respectively, for the three risk groups. The authors concluded in the study that functional decline among hospitalised elderly patients is common, and a simple predictive model based on four risk factors can be used on admission to identify elderly persons at greatest risk.

The chance of decline in the functional status in an old person can be mitigated by using simple predictive instrument (Cornette et al., 2006). Cornette et al (2006) conducted a prospective cohort study that included 625 patients aged 70 years and older hospitalised via the emergency room, for at least 48 hours, in two academic hospitals. The aim was to develop a predictive index that could be used on admission to identify older hospitalised people at risk of functional decline three months after discharge. Assessment was based on activities of daily living (ADL) scale and instrumental ADL scale, cognitive function, falls, polypharmacy, comorbidity, continence, mobility and self-rated health and at 1 and 3 months interval after discharge. A logistic regression model was then constructed to predict functional status three months later. A lower score on IADL pre-admission scale, MMSE score on admission lower than 15/21, history of fall in the previous year, age and poor self-perceived health were independent risk factors. The SHERPA (Score Hospitalier d'Evaluation du Risque de Perte d'Autonomie) index gave each risk factor a weight proportional to the odd ratios of the independent factors. This score ranged from 0 to 11.5. This range was collapsed into a 4-category index of low, mild, moderate and high.

Acute medical illness deterioration leading to further disability among hospitalised older populations can be tackled using the Hospital Admission Risk Profile (HARP), which helps identify patients who might benefit from comprehensive discharge planning, specialised care and experimental interventions. This was a multi-centre prospective cohort study developed in six acute care hospitals in the United States. The HARP made use of 29 ADL questions by using a cohort of 448 elderly to develop the instrument and a cohort of 379 cohort to validate it. Data were collected within 48 hours of admission, at discharge and three months after

discharge. It stratified older patients at risk of functional decline into low, intermediate and high risk (Sager et al., 1996).

2.5.2.4 Institutionalisation, Mortality and Functional Decline.

A risk score to estimate survival in nursing home residents with advanced dementia, the Advanced Dementia Prognostic Tool (ADEPT) (Mitchell, Miller, Teno, Davis, & Shaffer, 2010), was developed. This was a retrospective cohort study in the United States using the Minimum Data Set (MDS) assessments. Cox proportional hazards regression was used to model 12-month survival. Mitchell et al (2010) reported length of stay, age, male, dyspnea, pressure ulcers, total functional dependence, bedfast, insufficient intake, bowel incontinence, body mass index, weight loss, and congestive heart failure as predictors of survival. The AUC for the final model was 0.68. The risk score ranged from 0–32 points. Higher scores indicated worse survival. The risk score predicted six-month survival in advanced dementia with moderate accuracy.

In situations where certain demographic, medical and behavioural conditions are fixed or progressive and cannot be changed, prognostic scores and models are valid means of identifying and analysing modifiable risk factors responsible for functional decline. For example, in a study that predicted functional decline among older women in four geographical area of the United States, a validated clinical prediction model identified slow gait, short-acting benzodiazepine use, depression, low exercise level and obesity as risk factors responsible for functional decline in community dwelling women. The development of this simple prognostic model based on these modifiable risk predictors successfully classified community dwelling aged women into two risk categories of functional decline based on vigorous activities and basic activities (Liu, Gutierrez, Seeley, & Cummings, 2000).

In another study, a prognostic score, a Mortality Risk Index Score (MRIS) (Flacker & Kiely, 2003), was developed. The authors identified factors associated with 1-year mortality in newly admitted and long-stay (in nursing home longer than 1 year) nursing home residents by linking Minimum Data Set (MDS) information with data from the National Death Index and used these factors to create a useful tool for estimating risk levels for 1-year mortality. The study included data on 100,669 residents collected during full MDS assessments from June 1994 through December 1997. Characteristics that were considered potential risk factors were examined individually in bivariate proportional hazards models. Relevant factors were entered into a proportional hazards regression step-wise model. The strongest factors were selected for entry

into a multivariate proportional hazards analysis. A mortality risk index score was created for each resident by summing the value of each hazard ratio in the multivariate model for those who had the risk factor. Flacker et al (2003), reported 34% of newly admitted elderly individuals died within one year. Important factors for 1-year mortality were shortness of breath, unstable conditions, being male, 25% food uneaten, low functional ability, BMI less than 23 kg/m^2, cancer, pressure ulcer and bowel incontinence. The MRIS index range from 0 to 19. Those who had none of the risk factors were given a MRIS of 0, representing no risk.

2.6 Critical Overview

This review has provided useful insights into the significance of aged residential care admission for older adults and the strategic support processes put in place. This significant situation has been warranted not only by ageing but the burden of chronic conditions such as COPD leading to functional decline. Evidence that COPD greatly impacts on the health of an elderly leading to a reduction in the quality of life or requirement for prolonged assistance including risk of becoming functionally declined or dependent on others has been discussed.

The key factors that make older adults move into ARC have been discussed. The review highlighted the emotional and stressful situation ARC entry may have for the older population and their families. The stress stems from the fact that for many older adults, the loss of independence is inevitable and ARC entry may be necessary following a physical, emotional, cognitive and social deterioration. This review highlighted that knowing a person's ADL capabilities can help predict the chances of community-dwelling adults subsequently entering aged residential care when other confounding factors are also looked into. The differences between ethnic groups may reflect different ways of caring for older people and their chances of institutionalisation.

Furthermore, a history of falls has been shown to result in a decline in function, making the elderly lose confidence with regard to the ability to perform functional activities. Additionally, the review pointed out that chronic pain results in decreased quality of life, worsening frailty and eventual institutionalisation. With ageing, it was highlighted that decrease in functional capacity results in the likelihood of ARC entry. The literature details a person's ability to make daily decisions, to make themselves understood, and memory capability indicates the capacity to remain cognitive. High levels of cognitive impairment result in residential care entry among older adults. Regarding hospitalisation, physical recuperation of

older adults is more difficult and requires longer hospital stays, hence they often need to be discharged to residential care because of decreased functioning and the need for help. The decision to transition into a residential care is associated with changes in health and family structure, and gender. Many elderly are at risk of ARC admission once they start to live alone or lose a partner. However, despite all the attendant risks for the elderly to move into ARC, the literature established there are valid means of identifying and analysing such risks of decline and ARC entry through prognostic models and scores. Prognostic scores provide a pathway to make an informed decision.

In conclusion, there is ample evidence from literature that there is a general research on COPD and its risks of causing functional decline, the burden of ARC and the risk of entry for community dwelling older adults. However, there is little evidence from literature on what pulls these themes together. This thesis sets out to address this research gap. From the themes identified in the literature review, the prognosis for older adults within the interRAI COPD sub-population and likelihood of ARC entry can be investigated by modelling the pattern of transition to ARC for community dwelling elderly individuals. This model may then be used to stratify this sub-population into risk categories as an informed prognostic measure. For this study, the prognostic score characterises the 'Journey from an Independent to a Dependent-Living Environment' and is given the acronym 'JIDE score'.

The methods used to address this are detailed in the next chapter.

CHAPTER THREE

Methods

As discussed in Section 1.1, the population of New Zealand is ageing which comes with manifestation of chronic conditions such as COPD, a condition affecting more than 15% people of 45 years old and above. This condition has brought about issues associated with functional decline. Functional decline in this study is characterised with the Activity of Daily Living Hierarchy Scale.

interRAI tools provide a way to assess issues for people living in the community as well as those living in places such as Aged Residential Care. Based on known risks of ARC entry as discussed in Section 2.4 and Section 1.4 on the use of assessment instruments, it is possible for risk stratification scores as discussed in Section 2.5 to be developed and assess the risk of ARC entry.

This methods chapter sets out steps to achieve the goal of this study. The goal of the thesis is to assess the role of functional decline as risk factor for ARC admission among community dwelling COPD elderly and on the basis of the identified risk factors, develop a risk stratification score. To this end, data from interRAI was obtained and analysed to derive these estimates. Specifically, the research objectives were to;

1. Test the hypothesis that those with better ADL capabilities were less likely to enter ARC after controlling for all other potential confounding variables.
2. Develop a risk stratification score based on the predictive ability of associated variables that contributed to ARC entry. The composite score characterises the 'Journey from an Independent to a Dependent Living Environment' and is given the acronym 'JIDE score'.
3. Assess the incremental risk of ARC entry based on the JIDE score.
4. Test the hypothesis that those with better ADL capabilities have reduced hazard of ARC entry after controlling for all other potential confounding variables.

The purpose of this chapter is to describe in detail the research process, data analyses, and statistical procedures undertaken to meet the above objectives. The methods chapter is divided

into five sections. Section 3.1 outlines the setting of the study and the population studied. Section 3.2 provides an overview of the data sources and how they were accessed with a detailed description of the interRAI-HC instrument. In Section 3.3, a detailed description of the outcome variables and explanatory variables used in the study are discussed. In Section 3.4, the steps of univariate and bivariate analyses, explanatory multivariable regressions, risk stratification and cox regression are discussed. Section 3.5 sets out the ethical justification for obtaining and analysing the data and 3.6 summarises the action plan of the methods chapter.

3.1 Study Setting and Population

The participants and observation counts of this study were drawn from the interRAI data set for New Zealand (interRAI New Zealand, 2018b). This data set includes community-dwelling resident adults 65 years and older in New Zealand, who have undergone interRAI-HC assessment. This cohort of individuals (N =105,502) had consented at the time of their assessment for their data be used for planning and research purposes (Schluter et al., 2016). The period covered by the assessments was between 1st July 2012 and 26th January, 2016. For the purpose of this thesis, an individual was included in the analysis if he or she met all of the following criteria:

1. Was at least 65 years of age as at the time of first assessment.
2. Was diagnosed with COPD as captured by the interRAI-HC assessment instrument ((Section 1:1l), appendix A).
3. Was not in any imminent danger of death.
4. Lived within the community at the time of first assessment.

An individual was excluded from the analysis of data for this thesis if he or she:

1. Failed to meet any of the inclusion criteria, i.e., younger than 65 years, no COPD, not in imminent danger of death.
2. If first assessment occurred before 1st July, 2012 or after 26th January, 2016.

These inclusion and exclusion criteria resulted in 10,377 individuals being identified in the interRAI data set. A flowchart representation of how the sample size was derived is shown in Figure 3.1.

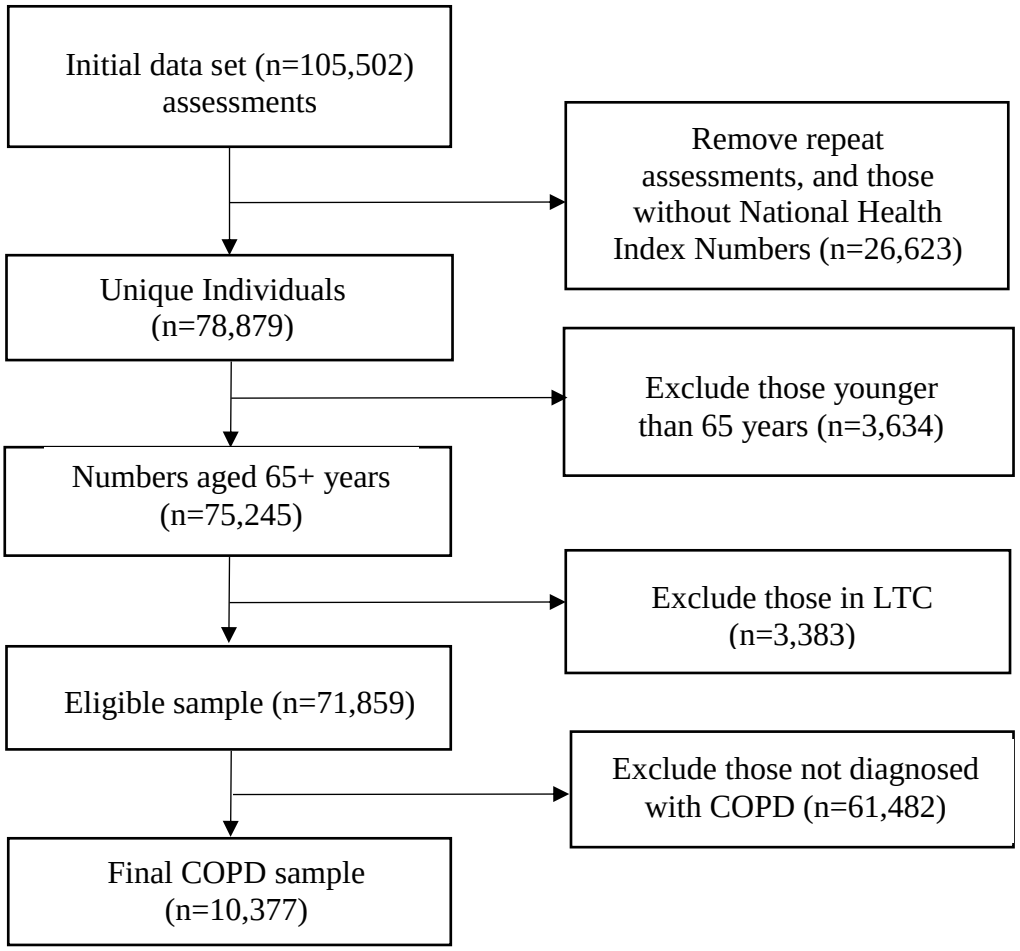

Figure 3.1: Flowchart of interRAI COPD sample size diagram

3.2 Data sources and access to data

3.2.1 Legal obligations of interRAI instruments.

As discussed in Chapter 1, the interRAI 'suite' of data collection tools includes one for home care assessment; interRAI-HC. This is used to assess the comprehensive care and service plans in community based settings focusing on a person's functioning and quality of life by assessing needs, strengths, and preferences, and facilitating referrals when appropriate. It is primarily used for adults in home and community-based settings, especially the frail elderly or persons with disabilities who are seeking or receiving formal health care and supportive services (interRAI, 2018).

The Ministry of Health of the Government of New Zealand (MoHNZ) holds the licence to use the adapted version of interRAI-HC 9.1 instrument for data collection (Ministry of Health, 2004). The royalty-free licence with interRAI International allows the New Zealand

Government, through the Ministry of Health, the right to use the instrument for collection of data and to maintain control over the data collected. Requests for access to unit record-level data are made through the National interRAI Data Analysis and Reporting Centre. The centre is responsible for the safeguarding the privacy, security, and confidentiality of interRAI clients/residents, aged residential care (ARC) facilities, and home and community support providers who provided the data in the first place. All data requests are conducted by completing an application form and emailing it to the centre. Depending on the complexity of the data request, there may be a fee involved for data processing (interRAI New Zealand, 2018b). Guiding principles used in processing requests in New Zealand are outlined below (interRAI New Zealand, 2018c).

- Ownership: All interRAI data collected in New Zealand on individual clients/residents, ARC facilities, and home and community support providers remains the property of the participating clients/residents. The interRAI New Zealand Governance Board acts as guardian of the interRAI data on behalf of interRAI New Zealand.
- Kaitiaki/Guardianship of the data: Once the requesting party receives access to interRAI data, it will act as guardian of the interRAI data collected from clients/residents, ARC facilities, home and community support providers and will ensure: that the data is held and used in accordance with the principles and provisions of the proposed protocols and that the data is analysed, interpreted, reported and published in culturally appropriate ways.
- Privacy of interRAI clients/residents, ARC facilities, home and community support providers: The data collected from and about interRAI clients/residents, ARC facilities, home and community support providers is used for purposes of quality improvement, research purposes, strategic service planning and development and ultimately to improve the health outcomes of older people. The privacy of individual clients/residents, ARC facilities, and home and community support providers must be preserved at all times. Any interRAI client/resident who has not consented for his/her personal information to be used for analytical or research purposes must be excluded when making unit record data available to any party. Once a requesting party receives access to interRAI data, it must comply with the Privacy Act 1993, Section 22 of the Health Act 1956, the Health

Information Privacy Code 1994, the Statistics Act 1973 (section 37) and any other relevant legislation.

- Security of interRAI data: Once the Centre approves the data access, interRAI data will be transferred by secured transmission processes to the requesting party. Once interRAI data is received, the requesting party must keep the data safe by using a secure data network. All information (e.g. National Health Index of clients/residents) will be encrypted during transfer, and only authorised users will be able to access it. When the study is completed, the requesting party will take the necessary steps to destroy the data from their network in a timely fashion. The requesting party will inform the Centre once this is done within 12 months of the completion of the study.
- Confidentiality when disseminating interRAI data: When the requesting party publishes any analysis or reports from the use of interRAI data, no individual client/resident, ARC facility, and home and community support provider should be able to be identified. The requesting party must ensure that release of interRAI data complies with the Official Information Act 1982, Privacy Act 1993, Health Information Privacy Code 1994, and any other relevant legislation. The requesting party must acknowledge the use of interRAI data by quoting the source as agreed by interRAI New Zealand and the MOH.
- Linking interRAI data with other datasets: interRAI data can be linked at various levels to a number of other health datasets including Pharmacy, National Minimum Dataset (NMDS), mortality, and hospitalisation. The requesting party must explicitly state the data sources to be linked to interRAI data in the application for data request. Data linkages are encouraged as long as the provisions for privacy, confidentiality and security are maintained.

3.2.2 The interRAI-HC instrument.

The instrument (see appendix A) consists of 236 questions (interRAI New Zealand, 2018a), which form more than 18 scales such as Activities of Daily Living Hierarchy Scale (ADLH), Social Withdrawal Scale, The Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS), CPS and the updated CPS; Cognitive Performance Scale 2 (CPS2), Depressive Severity Index (DSI), The Detection of Indicators and Vulnerabilities for Emergency Room Trips Scale (DIVERT), Instrumental Activity of Daily Living Involvement Scale (IADLI), Mania Scale, Pain Scale, Positive Symptoms Scale (PSS), Revised Index of

Social Engagement (RISE), Risk of Harm to Others (RHO), Self-Care Index (SCI), Severity of Self-harm (SoS) and Aggressive Behaviour Scale (ABS). CAGE Scale (Cutting down on substance use, being Angered by criticisms from others, feelings of Guilt about substance use and drinking/using 'Eye-opener' substances in the morning) (interRAI New Zealand, 2018d).

When information is collected through the interRAI-HC assessment, it is electronically archived by the interRAI Services department. Each individual in New Zealand who has used health services is provided a unique identifier referred to as the National Health Index (NHI) (Downes, Dever, & Douglass, 2010; Ministry of Health – Manatu Hauora, 2014; Schluter et al., 2016). All individuals in the interRAI-HC-9.1 database have an NHI; in order to ensure a robust and comprehensive data set, using encrypted security, the NHI is used to link to records in other databases.

Other data bases that have been linked to interRAI data include ARC entry status and date of entry. ARC entry status is the transitioning of an individual from his/her place of residence to supported living. In this study, it has been coded as "ARC entry=YES (1)" and "ARC entry=NO (0)". ARC entry status and date of entry data were obtained from the Ministry of Health's Contracted Care Payment System (CPSS) database. The CPSS includes all individuals who are publicly funded for such care. Additionally, as information is voluntarily entered by providers, CPSS contains information on about 50% of those individuals who seek publicly funded care but are self-funded. Mortality information was extracted from the National Mortality Collection Register held by the MoHNZ. The population register to capture relevant indices including ethnicity and age is also linked (Schluter et al., 2017; Hirdes et al., 2008).

The linking of additional information to that collected using the interRAI instrument was undertaken by the Technical Advisory Service (TAS), a professional services organisation, providing a range of strategic, advisory and programme management services to the health sector. This organisation is funded by the Ministry of Health and includes experts in data analysis and health system applications (TAS Kahui tuitui tangata, New Zealand, 2018).

For this research, the interRAI-HC Assessment form (the New Zealand Customised version) was the source of data. This standardised and comprehensive document consists of 236 questions focused on more than 17 key domains. The instrument is partitioned into 20 domains

named as follows and listed according to their position in the questionnaire (refer to appendix A);

- **Identification Information:** This section captured relevant information about gender, age, marital status, NHI identifier, reason for undergoing assessment and when the particular date the assessment was done, residential status as at time of assessment as well as the living arrangement of the individuals at the time of assessment compared to the last 90 days. Time since last hospital stay and confirmation of the consent to use data collected anonymously for research purposes were also included.
- **Intake and Initial History:** This section captured the ethnicity the individual identified with, language spoken and residential history in the last 5 years.
- **Cognition**: This section captured information about the cognitive skill for daily decision making, memory recall ability, episodes of periodic disordered thinking as well as episodes of acute change in mental status from an individual's usual functioning.
- **Communication and Vision**: This section captured how an individual expresses information content both verbal and nonverbal, how verbal information content is understood with or without hearing aids, the ability of an individual to hear and the ability to see in adequate light with or without visual aids.
- **Mood and Behaviour:** This section captured information about indicators of possible depressed, anxious or sad mood, self-reported mood, and behavioural symptoms such as verbal abuse, wandering, socially inappropriate actions and resistance to care provision.
- **Psychosocial Wellbeing:** Social relationships, the expression of loneliness, decline in the level of participation in activities of interest and episodes of life stresses such as severe illness/death of close acquaintance, home or income loss are some of the information captured under this section.
- **Functional Status:** This section captured information about the ability to perform routine daily activities expected for normal living, episodes of exercises and decline in the performance of these activities.
- **H-Continence:** This section captured information about the frequency or ability to control movements of the bowels and bladder.

- **Disease Diagnoses:** Information about the presence or absence of disease or infection that the doctor has indicated to be present and affects the individual status, requires treatment or symptom management are captured in this section.
- **Health Conditions**: Other health conditions information not considered diseases such as fall history, use of alcohol and tobacco are captured in the section.
- **Oral and Nutritional Status:** Information about body mass index, nutritional intake, oral or dental hygiene are captured in this section.
- **Skin Condition:** Skin related symptoms are captured in the section.
- **Medications**: The type, history and administration of medications of an individual are captured in this section.
- **Treatment and Procedures:** Information about the type of treatment, prevention and procedural programmes as well at the type of formal care are captured in this section.
- **Responsibility:** Information about who is responsible for the decision making about an individual, what kind of advanced directives and EPOA plans are captured in this section.
- **Social Support**: This section captured information about the type and source of informal care.
- **Environmental Assessment**: This section covered information about the environment in which an individual is living. Such information include the state of the home, accessibility within and around the home, personal safety, heating and cooling.
- **Discharge Potential and Overall Status:** Information captured in this section gives an overall welfare status of an individual.
- **Discharge:** This section captured more information about last hospital stay and to where the person was discharged.
- **Assessment Information:** The assessor completing the assessment information is captured in this section.

Attached in the appendix (appendix A) is a complete interRAI-HC instrument.

3.3 Outcome and Explanatory Variables

The variables used in this study are as follows:

Aged Residential Care (ARC) entry was the outcome variable. This variable refers to the process of the transitioning of an individual from place of residence, in this case home, to a residential care setting following a comprehensive interRAI assessment. It was binary coded as follows "0 = NOT EnteredARC and 1= EnteredARC", where EnteredARC is the variable name.

Time to ARC Entry was another outcome variable. This outcome variable refers to the time between the points of first assessment to the time that an individual entered ARC. The hazard estimated gave the risk of ARC entry per unit time during this period. This is measured in the number of days. The relationship between ARC entry (outcome variable) and the extent to which explanatory variable explain why elderly move into ARC was hypothesised below;

Hypothesis H_0: Overall risk of entry to ARC for elderly individuals will be similar for those with high and low scores on activities of daily living after controlling for confounders.

Hypothesis H_1: Elderly individuals with better ADL capabilities were less likely to enter ARC after controlling for all other potential for confounders.

The hazard (time to event) of ARC entry based on the associated explanatory variables after undergoing interRAI assessment was hypothesised below;

Hypothesis H_0: Overall hazard of entry to ARC for elderly individuals will be similar for those with high and low scores on activities of daily after controlling for all other potential for confounders.

Hypothesis H_1: Elderly individuals with rapid functional decline in ADL have an increased overall hazard (time) to transitioning into ARC after controlling for confounder.

Covariates included in this study were those identified in the literature review that have been found to be associated with both low ADL and ARC entry as discussed in Section 2.4.

- Activities of Daily Living(ADL)
- Age in years
- Relationship status
- Living arrangements
- Cognition
- Depression
- Bladder continence
- Gender
- Pain
- Fall history
- Loneliness
- Ethnicity
- Time in hospital

A diagrammatic representation of the conceptual diagram of the relationship between the outcome variables and the explanatory variables in this study is shown in Fig 3.2

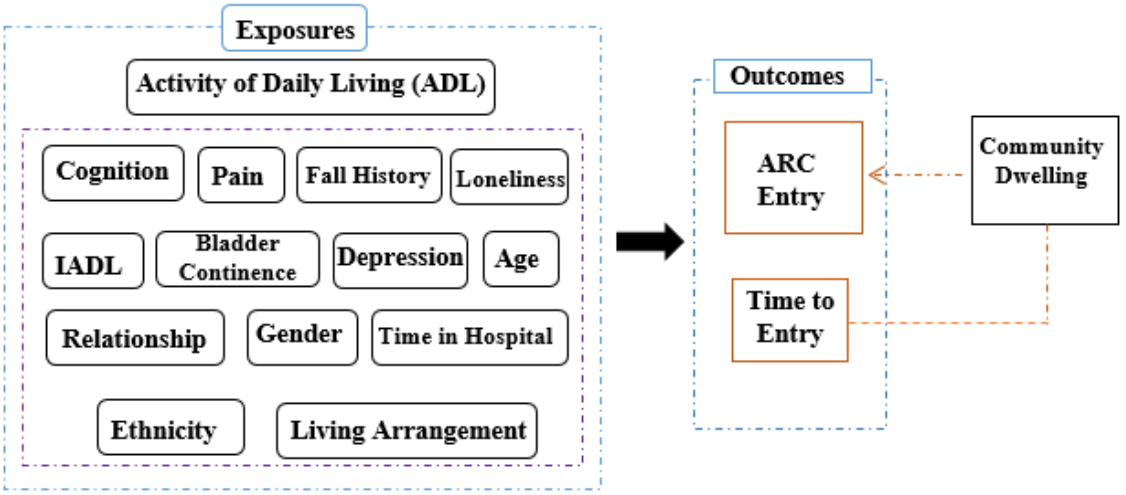

Figure 3.2: Conceptual diagram of study

The variables retrieved from the interRAI-HC instrument (Appendix A) treated as explanatory variables in this study are set out below along with details about how individual variables were recoded for use in the study. The recoded variables are presented in Table 3.1.

Variables include:

Age in years (**A3**) was derived using the formula of date of birth minus date at first assessment.

Gender (**A2**) response options were male and female.

Ethnicity (**B2**) was coded as follows; Māori as 1 followed by Pasifika (2), Asian (3), European (4) and Other (5).

Relationship Status (**A4**) was elicited with six response options: never married; married/civil union/de facto; widowed; separated; divorced; other. For these analyses, separated, divorced and others categories were combined to form four (4) categories recoded as never married (1), married or in civil union (2), widowed (3) and others (4).

Table 3.1: Final coding of explanatory variables retrieved from interRAI instrument.

Variable	**Description**	**interRAI-HC**
Age in years	Difference between 1st assessment and date of birth	A3
Gender	Male', 'Female'	A2
Ethnicity	Māori = 1	B2
	Pasifika = 2	
	Asian = 3	
	European = 4	
	Others = 5	
Relationship status	Unmarried = 1	A4
	Married = 2	
	Widowed = 3	
	Others = 4	
Living arrangement	Alone = 0	A13a
	With someone = 1	
Fall history	None in previous 90 days = 0	J1
	At least one in previous 90 days = 1	
Loneliness	No', 'Yes'	F2
Cognitive Performance Scale	Combination of four items to form a scale ranging from 0 to 6	C1, C2,C3,C4,C5
ADL Hierarchy Scale	Combines four items to create a seven-category score	G2
IADL Scale	Combines eight items to create a seven-category score	G1
Depression Rating Scale	Summation of seven items gathered over a 3 day period to form a score that ranges from 0 to 14	E1
Pain Scale	Summarises frequency of pain complaints and the score ranges from 0-4	J6a

Living arrangements (**A13a**) at the time of the assessment had response options: alone, with spouse/partner only, with spouse/partner and other(s), with child (not spouse/partner), with parent(s) or guardian(s), with sibling(s), with relatives, and with non-relative(s). The categories (spouse/partner only, with spouse/partner and other(s), with child (not spouse/partner), with parent(s) or guardian(s), with sibling(s), with relatives, and with non-relative(s)) were combined to create categories "living alone" and "living with someone else". For the purpose of this study, therefore living alone and living with someone were the two categories used. They were re-coded as living alone (0) and living with someone as (1).

Falls (**J1**) were reported in four categories (no fall in the last 90 days, no fall in the last 30 days but fell 31-90 days ago, one fall in the last 30 days and two or more falls in the last 30 days). The categories were re-coded into two groups; no falls in the last 90 days (0) and at least one fall in the last 90 days (1).

Loneliness (**F2**) response options were indicated by asking if a resident feels lonely or not and coded as NO (0) and YES (1).

Cognitive impairment (**C1, C2, C3, C4, and C5**) was assessed using the Cognitive Performance Scale (CPS). This scale describes the cognitive status of a resident (Morris et al., 1994) by combining five items from the interRAI-HC instrument (daily decision making, memory recall ability, periodic disordered thinking or awareness, acute change in mental status, change in decision making) to create a seven-category score: intact; broad-line intact; mild; moderate; moderate severe; severe; and, very severe. The scale ranges from 0-6. Higher scores indicate more severe cognitive impairments.

Participation in Activities of Daily Living (ADL) (**G2**) was assessed using the ADL Hierarchy Scale, (Morris, Fries, & Morris, 1999) which combines four items (personal hygiene, toilet transfer, locomotion, and eating) to create a seven-category score: independence; supervision; limited; extensive; maximal; dependent; and, total dependence. The ADL hierarchy scale reflects the disablement process by grouping ADL performance levels into discrete stages of loss. The early loss is characterised by inability to carry out personal hygiene. Middle loss is inability to perform toileting and locomotion while late loss is characterised by loss if ability to eat. The score ranges from 0-6. Higher scores indicate greater decline (progressive loss) in ADL performance.

Instrumental Activities of Daily Living (IADL)(**G1**) combines eight items (meal preparation; ordinary housework; managing finances; managing medications; phone use; stairs; shopping; and, transportation) to derive a score ranging from 0 (complete independence) to 48 (total dependence). This scoring was used to elicit the capacity and performance ability of the resident (Morris, Berg, Fries, Steel, & Howard, 2013).

Depression (**E1**) indication within the last 3 days was assessed by the Depression Rating Scale (Burrows, Morris, Simon, Hirdes, & Phillips, 2000). The scale was created by summing seven items (made negative statements; persistent anger with self or others; expressions (including non-verbal) of what appear to be unrealistic fears; repetitive health complaints; repetitive anxious complaints/concerns (non-health-related); sad, pained, worried facial expression; and, crying, tearfulness) to form a score that ranges from 0 to 14. A score of 3 or more may indicate a potential or actual problem with depression. Each individual in the interRAI-HC data has a generated DRS score (Burrows et al., 2000) which was used in this study.

Pain Scale (**J6a**) summarises the presence or intensity of pain by summing the frequency with which a person complains or shows evidence of pain and intensity of the highest level of pain present. The score ranges from 0-4 (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001). Higher scores indicate more severe pain. Each individual in the interRAI-HC data has a generated pain score (Fries et al., 2001) which was used in this study.

3.4 Data Analysis

Statistical analyses were conducted using the free and open-source R software for statistical computing, version R-3.5.0 (R Core Team, 2018). The steps consisted of pre-processing and univariate analysis; bivariate regression analysis; multivariable regression analysis; composite risk stratification; and survival analysis. In univariate analysis, individual variables are summarised and patterns within the data described. Bivariate analysis is a statistical measure of finding out the existence of relationship between two variables. Multivariable regression analysis is based on models used to establish the relationship between a response variable (i.e. an outcome of interest) and more than one explanatory variable. Common types of multivariable regression are linear regression, logistic regression and Cox proportional hazards regression. Risk stratification is the process of identifying and assigning a risk based on the predictive ability of models. Survival analysis is a set of methods for analysing data where the outcome variable is the time until the occurrence of an event of interest

including competing risk. Competing risks data occur when the interest is focused on a specific cause of failure in the presence of other different causes, which alter the probability of experiencing the event of interest

3.4.1 Pre-processing of data.

The data set was pre-processed by identifying outliers, missing values, and values in the data set that may be outside of the expected range (beyond outliers). For variables that were treated as continuous, outliers were those data points that, on a box plot, lay beyond a 1.5 time IQR or interquartile range from the 75th percentile value. For categorical data, single variable distribution tables with count and percentages were examined to see if these variables contain values that were beyond their reasonable ranges.

3.4.1.1 Univariate Analysis.

Univariate analysis captured summary statistics for each variable in the selected data set of 10,377 as described in Figure 3.1. The variables treated as continuous variables are shown in Table 3.2.

Table 3.2: Explanatory variables treated as continuous

Variable	**Description and measures (mean, SD)**
Age in years	Age completed in years
Pain Scale	Score ranges from 0 to 4
DRS Scale	Score ranges from 0 to 14
IADL Performance Scale	Score ranges from 0 to 48
Bladder Continence	Score ranges from 0 to 8

In finding these values, each considered as continuous in the data set was described using a 'five number summary'. A continuous variable in this study was defined as a variable that has an infinite number of possible values. For the continuous variables, mean and standard deviation were reported.

The variables as categorical variables are shown in Table 3.3. Variables considered as categorical were those that take on one of a limited and usually fixed number of possible values, assigning each individual or other units of observation to a particular group or nominal category on the basis of some qualitative property. For these categorical variables, frequency distribution and reporting the number (or frequency) of individuals per category and associated percentages were analysed.

Table 3.3: Explanatory variables treated as categorical.

Variable	Description and measures (frequency and percent ages)
Gender	"Male", "Female"
Ethnicity	"Māori", "Pasifika", "Asian", "European", "Others"
Relationship status	"Unmarried", "Married", "Widowed", "Others" Living
arrangement	"Alone", "With someone"
Fall history	"None", "At least one"
Loneliness	"NO", "YES"

3.4.2 Bivariate Analyses: Likelihood of entry to ARC.

The unpaired two-sample t-test was used to compare the mean of two independent groups. Tables were produced for individual variables, both continuous and categorical. The mean and standard deviations were also specified as well as the *p* -values of significance. The Test of Independence assessed whether an association exist between the two variables by comparing the observed pattern of responses in the cells to the pattern that would be expected if the variables were truly independent of each other.

Regression is concerned with the description of the relationship between a response or outcome variable and one or more explanatory variables (Harrell, 2015). Logistic regression provides a method for modelling a binary response variable, which takes values 1 and 0. In this study, the outcome variable "ARC Entry" is discrete, taking on two possible values. It was coded as a binary variable ("yes" or "no") and in order to explain the relationship between this dichotomous response and explanatory variables, a bivariate logistic regression was carried out to explain the relationship between the outcome variable "ARC entry" and individual explanatory variables as well as multivariable regression to know the effect of functional decline on ARC entry in the presence of other explanatory variables.

Denoting "ARC entry" as Y=0 or 1 with Y=1 denoting occurrence of event i.e. entered ARC.

Based on the works of Cox (1958), Walker et al. (1967) and Harrell Jr. (2015) , letting X denote the vector of explanatory variables as listed in Section 3.3, $\{X_1,X_2,...,X_k\}$, the probability that Y=1 given X, is given as:

$$Prob\{Y = 1|X\} = [1 + exp(-X\beta)]^{-1} \qquad (3.1)$$

where , $X\beta = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + ... + \beta_k X_k$, and β, represent the estimated parameters by the maximum likelihood method.

Because the variables x have unlimited range in values, the logistic function is better expressed in terms of the variables in order to restrict the probability P = Prob (Y =1|X) to range from 0 to 1,

$$P = [1 + exp(-x)]^{-1} \qquad (3.2)$$

and solving the equation above for x using;

$$1 - P = exp(-x)/[1 + exp()(-x)] \qquad (3.3)$$

yields the inverse of the logistic function;

$$x = \log\left[\frac{P}{1-P}\right] = \log[odds \text{ that } Y = 1 \text{ occurs}] = logit\{Y = 1\} \quad (3.4)$$

Logistic regression is able to deal with the non-linear violation by using a logarithmic transformation on the outcome variable which allows the modelling of non-linear association in a linear way. Hence,

$$\begin{aligned} logit\{Y = 1|X\} &= logit(P) \\ &= \log\left[\frac{P}{1-P}\right] \\ &= X\beta \end{aligned} \qquad (3.5)$$

The model in this form now assumes that for every explanatory variable X_j,

$$logit\{Y = 1|X\} = \beta_0 + \beta_1 X_1 + \ldots + \beta_j X_j + \ldots + \beta_k X_k = \beta_j + C, \quad (3.6)$$

where if all other explanatory variables were held constant, *C* is given by

$$C = \beta_0 + \beta_1 X_1 + \ldots + \beta_{j-1} X_{j-1} + \beta_{j+1} X_{j+1} + \ldots + \beta_k X_k \quad (3.7)$$

and expressing the relationship in terms of odds that *Y*=1;

$$odds\{Y = 1|X\} = exp(X\beta), \quad (3.8)$$

and if all factors other than X_j are held constant,

$$odds\{Y = 1|X\} = \exp(\beta_j X_j + C) = exp(\beta_j X_j) exp(C) \quad (3.9)$$

These regression parameters can also be expressed in terms of odds ratios, i.e. the odds that *Y*=1 when X_j as increased by d, divided by the odds at X_j is;

$$\begin{aligned} Odds\ Ratio &= \frac{o\ d\ ds\{Y = 1|X_1, X_2, \ldots, X_j + d, \ldots X_k\}}{o\ d\ ds\{Y = 1|X_1, X_2, \ldots, X_j, \ldots X_k\}} \\ &= \frac{\exp[\beta_j(X_j + d)] \exp(C)}{[\exp(\beta_j X_j) \exp(C)]} \\ &= \exp[\beta_j X_j + \beta_j d - \beta_j X_j] \\ &= \exp(\beta_j d) \end{aligned} \quad (3.10)$$

Thus the effect of increasing X_j by d is to increase the odds that *Y*=1 by a factor of exp (β_jd), or to increase the log odds that *Y*=1 by an increment of β_jd.

The bivariate logistic regression for explanatory variables defined as binary or dichotomous was captured as;

$$\begin{aligned} logit\{Y = 1|X = 0\} &= \beta_0 \\ logit\{Y = 1|X = 0\} &= \beta_0 + \beta_1 \end{aligned} \quad (3.11)$$

where, β_0 is the log odds that Y=1 when X=0. β_1 is the log of the ratio of the odds when X=1 compared to the odds when X=0. The value exp (β_1) is the odds ratio for a single dichotomous explanatory variable X=1 compared to X=0, the bivariate logistic regression for a continuous explanatory variable is;

$$logit\{Y = 1|X\} = \beta_0 + \beta_1 X, \qquad (3.12)$$

explaining that an increase in X by one unit increases the odds by a factor of exp(β_1)

A bivariate regression model whether it is linear regression or non-linear regression, provides a crude estimate of the association between an explanatory variable and an outcome variable. As there are confounding covariates that are associated both with the explanatory variable and the outcome variable, and are not in a causal chain, in order to adjust for the effects of the confounding variables, the examination of the association between the explanatory and the outcome variable was done through the exploratory multivariable regression as discussed in Subsection 3.4.3.

3.4.3 Multivariable Modelling

The Multivariable approach focuses on assessing association between a single outcome variable and multiple explanatory variables. The goal of the thesis was to model the pattern of transition to ARC for community dwelling elderly patients with COPD and test the hypothesis that those with better ADL capabilities were less likely to enter ARC after controlling for all other potential confounding variables. These explanatory variables are listed in Section 3.3 and denoted as $X= (X_1, X_2, ..., X_k)$. The multivariable logistic regression model is expressed as;

$$C(Y|X) = Prob\{Y = 1|X\} = (1 + exp(-X\beta))^{-1}, \qquad (3.13)$$

where ARC entry Y value were either 0 or 1 and β is the regression coefficient and $C(Y|X)$ denotes the property distribution of Y given the values of X. The transformed model is expressed as

$$C(Y|X) = log(exp(X\beta)) = X\beta \qquad (3.14)$$

For this regression model, β is the change in the log odds that ARC entry (Y=1) per unit change in X. Thus the effect of increasing X_j by d is to increase the odds that Y=1 by a factor of exp (β_jd), or to increase the log odds that Y=1 by an increment of β_jd.

The Multivariable regression was conducted through a logical sequence of adding and subtracting variables so that the final model can explain and predict the likelihood of a person's entry to aged residential care.

3.4.3.1 Modelling strategy.

The data set was divided into two groups; a training dataset made up of 70% of observations and a testing data set comprising the remaining 30%. The training set was used to build the model and the testing data was used to validate the model as is standard practice or convention. Using the results of the validation, a composite score was developed based on the combinations of explanatory variables. The purpose of this was to stratify the likelihood of transition to ARC into the following groups: "low", "medium", "moderate", and "high". Low likelihood of transition is the category where the risk of ARC entry is very low, mild likelihood of transition is the category where the risk of ARC entry is not substantial, moderate likelihood of entry is the category where the risk of entry is significant and high likelihood of transition is the category for those who have immediate risk of being admitted to ARC. The stratification score to partition the ARC transition probabilities is based on a common set of relevant explanatory variables.

This approach of variable selection and explanatory model building has been chosen for the following reasons:

1. The aim of this study was to develop an explanatory model of entry to ARC for elderly patients with COPD using a clinically relevant instrument, and by using this instrument, develop a meaningful stratification algorithm. As interRAI is based on a practice setting, all variables included were either biologically relevant, or were clinically admissible. Hence the regression strategy was based on clinical epidemiology approach.
2. As a result, the aim was to develop the "best explanatory" model, not necessarily the "most parsimonious model", with "fewest" possible variables.
3. This was why the modelling started with first a set of bivariable models, selecting the ones that had highest effect sizes, and kept comparing the effect

sizes. If the effect sizes differed substantially between the bivariable and the multivariate model (say by 20% or more), then it could be said that one variable was confounded by another (i.e. the one with most deviated beta coefficient confounded by the one with least deviated beta coefficient) and that variable could either be dropped or transformed if there was a thought there might be collinearlity (i.e. the two variables express the same concept).

The model building continued this way until the variables that were considered to contribute to the best explanatory model were exhausted.

3.4.3.2 Step by step model building process.

1. From the bivariate logistic regressions, beta coefficients of every explanatory variable were computed. Further, based on theoretical considerations of what is known in the literature about people entering ARC, 12 variables were considered for the models. Subsequently, for all such variables, their beta coefficients based on logistic regression were computed and rank ordered. As the primary explanatory variable here was ADL, this was the main variable entered into all subsequent multivariable models. All other variables that were deemed as possible confounders, were added in the sequence of their ranked beta coefficients. The principles of inclusion and exclusion of the variables in subsequent models are described in Step 2.
2. After the selection of these variables as explained above, following the principles laid by Hosmer and Lemeshow (1999), a step-wise multivariable logistic regression was conducted starting with two variables: ADL (the main explanatory variable), and another variable that had the largest magnitude of beta coefficient in absolute value. After completion of one step, a variable was either eliminated from a subsequent model or retained based on whether the variable showed a change in the coefficient value or sign. Such change indicated that the variable was being confounded by ADL and there- fore would not be included in a subsequent model.

   The level of significant change was deemed to be that of 20%. If the ‘sign’ changed from a ‘positive’ to ‘negative’ (or a ‘negative’ to ‘positive’) then the variable was dropped. Additionally/alternatively, if the magnitude of the beta

coefficient dropped by 20% or more from its crude value, then the variable was dropped from being included in a subsequent model, as this indicated substantial confounding by ADL. Otherwise, the variable was retained in a subsequent model. These two criteria are considered sufficient for retaining a variable in the working model. Iteratively the two criteria are assessed for all variables until no further variable is removed.

3. Once these models were built and validated, outcomes from the models were used to build a stratification score to partition the ARC transition probabilities based on a common set of relevant explanatory variables. A detailed description of how this was done is set out in Section 3.4.4

3.4.4 Journey from Independent to Dependent-Living Environment (JIDE Composite Score)

The stratification was based on the outcome of the multivariable analysis. A composite score for each observation in the testing data set was developed. The composite score was equal to the sum of the product of the beta coefficient of each explanatory variable in the final model and their values as presented in the interRAI assessment data. The Composite Score derivation is denoted as;

$$Cs = \sum_{N=1}^{N} K_N \beta_N \qquad (3.15)$$

where Cs is the composite score of each observation in the test data; the sum of the product of the beta coefficient of each explanatory variable in the final model and their values as presented in the interRAI assessment data, K_N are the explanatory variables and (β_N) are the beta coefficient values derived from the final multivariable model.

For example, denoting the explanatory variable 'loneliness' as K and assuming loneliness is a potential explanatory variable retained in the final model, and denoting its beta coefficient to be β derived from the multivariable regression, the predictive value of loneliness will be the product of the beta coefficient of loneliness in the final model and its values ("not lonely=0" and "lonely=1") as presented in the interRAI assessment data.

The performance of the stratification score was tested on the basis of constructing a Receiver Operating Characteristic (ROC) curve under the predictor model to determine the proportion of ARC entry attributable to a predictor based on the confusion matrix. The confusion matrix was formed from the four outcomes produced as a result of binary classification of ARC entry. These four outcomes were; true positive, true negative, false positive and false negative;

1. True positive (TP): This was the correct positive prediction of ARC Entry
2. False positive (FP): This was the incorrect positive prediction of ARC Entry
3. True negative (TN): This was the correct negative prediction of ARC Entry
4. False negative (FN): This was the incorrect negative prediction of ARC Entry

The confusion matrix of ARC entry binary classification is a two by two table formed by counting of the number of the four outcomes of a binary classifier as shown in Fig 3.3

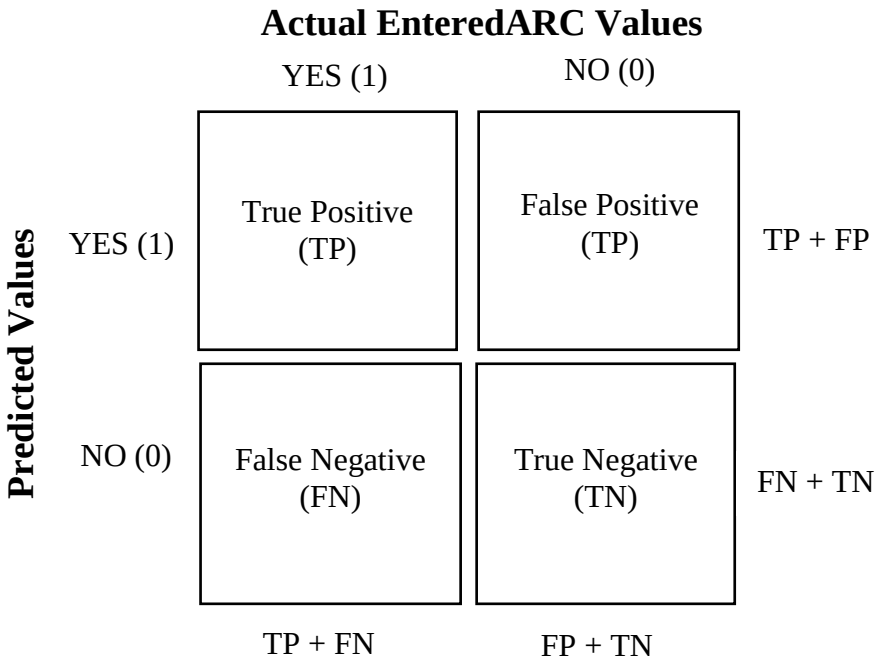

Figure 3.3: ARC Entry Confusion Matrix

Sensitivity and specificity constitute the basic measures of performance of diagnostic tests. Sensitivity or True Positive Rate (TPR) is the conditional probability of correctly identifying those who entered ARC or the number of correct ARC entry positive predictions divided by the total number of positives which is given by;

$$S_N = \frac{TP}{TP + FN} \qquad (3.16)$$

Specificity or True Negative Rate (TNR) is conditional probability of correctly identifying those who did not enter ARC or the number of correct ARC entry negative predictions divided by the total number of negatives which is given by;

$$S_P = \frac{TN}{TN + FP} \qquad (3.17)$$

False Positive Rate (FPR) is the conditional probability of positive outcome for those who did not enter ARC or the number of incorrect ARC entry positive predictions divided by the total number of negatives. It is related to Specificity as shown in the equation;

$$\begin{aligned} FPR &= \frac{FP}{TN + FP} \\ &= 1 - \frac{TN}{TN + FP} \\ &= 1 - S_P \end{aligned} \qquad (3.18)$$

False Negative Rate (FNR) is the conditional probability of negative test for those who entered ARC which is given by;

$$FNR = \frac{FN}{TP + FN} \qquad (3.19)$$

Positive Predictive Value (PPV) is the number of correct positive predictions of ARC entry divided by the total number of positive predictions. It can also be called the precision. It is expressed as;

$$PPV = \frac{TP}{TP + FP} \qquad (3.20)$$

Error rate (ERR) is the number of all incorrect ARC entry predictions divided by the total number of the dataset.

$$ERR = \frac{FP + FN}{TP + FP + FN + TN} \qquad (3.21)$$

Accuracy (ACC) is the number of all ARC entry correct predictions divided by the total number of the dataset. It is also obtained by 1 – ERR;

$$ACC = \frac{TP + TN}{TP + FP + FN + TN} \qquad (3.22)$$

The Receiver Operating Characteristic (ROC) curve is a model-wide evaluation measure based on two basic evaluation measures – specificity and sensitivity derived from the confusion matrix. The Receiver Operating Characteristic (ROC) curve is a graphical display of sensitivity (TPR) on y-axis and (1 – SP = FPR) on x-axis for varying cut-off points of test values. It is an effective method of evaluating the quality or performance of diagnostic tests.

In this study, denoting X_j as the vector of explanatory variables (X_1, X_2, ..., X_k) and Y as the outcome variable for the population of those who entered ARC and those who did not, and letting F and G be the distribution functions of the random variables X_j and Y. The sensitivity of the test is given by;

$$S_N(c) = 1 - G(c), \qquad (3.23)$$

and the specificity is expressed as;

$$S_P(c) = F(c) \qquad (3.24)$$

where (c) is the appropriate cut-off point and outcome value is positive if it is greater than (c) and negative otherwise.

The ROC curve is defined as a plot of SN(c) versus 1-SP(c) for $-\infty \leq \infty$, or equivalently as a plot of;

$$ROC(t) = 1 - G(F^{-1}(1 - t)), \qquad (3.25)$$

over $t \in [0, 1]$, where $F{-}1\ (1 - t) = \inf \{x \in R : F\ (x) \geq 1 - t\}$.

The ROC curve is increasing and invariant under any monotone increasing trans- formation of the variables X_j and Y.

One of the most popular measures is the Area Under the ROC Curve (AUC). AUC is a combined measure of sensitivity and specificity. AUC is a measure of the overall performance of a diagnostic test and was interpreted as the average value of sensitivity for all possible values of specificity i.e. a criterion to measure the test's discriminative ability, i.e. how good is the test in a given situation. It is expressed mathematically as;

$$AUC = \int_0^1 ROC(u)\mathrm{d}u \qquad (3.26)$$

The AUC assumes that the best cut-off point for balancing the sensitivity and specificity of a test is the point on the curve closest to the (0, 1) point. Optimal sensitivity and specificity are defined as those yielding the minimal value for $(1-Sensitivity)^2 + (1-Specificity)^2$ (Perkins & Schisterman, 2006). The cut-off point corresponding to these sensitivity and specificity values was the one closest to the (0, 1) point and was taken to be the cut-off point that best differentiates between individuals who entered ARC and those who did not. Hence, the AUC was interpreted as the probability that, in a randomly selected pair of those who entered ARC and those who did not enter ARC, the risk test value was higher for those who entered ARC, i.e., AUC = $P(Y > X)$. Values of AUC close to 1 suggest a high diagnostic accuracy of the test (Gonçalves, Subtil, Oliveira, & Bermudez, 2014; Zhou, McClish, & Obuchowski, 2009; Obuchowski, 2003; Hosmer & Lemeshow, 2000; R. Kumar & Indrayan, 2011).

3.4.5 Time to entry to ARC.

Cox Regression method was used to analyse data where the outcome variable was the time until the occurrence of an event of interest. In this study, the outcome variable is the time until ARC entry occur i.e. the time from the first assessment to ARC entry.

3.4.5.1 Kaplan-Meier Estimation.

For the outcome variables where time to event were indicated with categorical variables as explanatory variables, the Kaplan Meier Survival curves for the pairs were compared and examined for the equal proportionality of Hazards. Kaplan–Meier analysis measured the survival time from first assessment until the time ARC entry or until an individual

was censored. This non-parametric method estimated the survival probability distribution of individuals who did not transition into ARC for certain period after interRAI assessment. Based on the work of Kaplan and Meier (1958), the equation that gives the Kaplan-Meier estimate is as follows;

$$S(t) = \prod_{j=1}^{i} (1 - \frac{d_j}{n_j}), \qquad (3.27)$$

where for any of the $t=t_1,t_2,...,t_k$ which denoted the unique ARC entry times in rank ordered manner, the estimated survival probability was $S(t)$, d_j was the number of individuals who went into ARC, while n_j was the number of individuals at risk at time t_i.

The use of the Kaplan-Meier method can be limiting in that the log-rank test is purely a significance test and cannot provide an estimate of the size of the difference between the groups and its related confidence interval. The Kaplan–Meier method and the log-rank test can only study the effect of one factor at the time, and therefore they cannot be used for multivariate analysis.

3.4.5.2 Cox Proportional Hazard Regression.

For these purposes, a regression technique, the Cox proportional hazards model based on the works of Cox (1972) and further discussed by Harrell (2015) and Dabrowska et al (1992).

Denoting T to be the non-negative random variable representing the waiting time until the occurrence of ARC entry, the survival function, $S(t)$ is given by;

$$S(t) = Pr\{T > t\} = 1 - F(t) \qquad (3.28)$$

where $F(t)$ was the cumulative distribution function for T. In this case, as the event was ARC entry, $S(t)$ was the probability that ARC entry occurred after time t or the probability that an individual survived ARC entry at least until time t. All individuals in this study had $S(t)$ to be 1 when $t=0$.

The distribution of T was characterised by the hazard function, $\lambda(t)$. This was the instantaneous rate or risk of ARC entry. The hazard at time t is related to the probability that ARC entry will

occur in a small interval around *t*, given that it has not occurred before time *t*. The function is expressed formally as;

$$\lambda(t) = \lim_{dt \to 0} \frac{Pr\{t \leq T < t + dt | T \geq t\}}{dt} \qquad (3.29)$$

The numerator of this expression is the conditional probability that ARC entry will occur in the interval (*t*, *t* + *dt*) given that it has not occurred before, and the denominator is the width of the interval. Dividing one by the other a rate of event occurrence per unit of time was obtained. Taking the limit as the width of the interval down to zero, an instantaneous rate of occurrence was obtained.

The conditional probability in the numerator was then written as the ratio of the joint probability that *T* is in the interval (*t*, *t* + *dt*) and $T \geq t$ (which is, of course, the same as the probability that *t* is in the interval), to the probability of the condition $T \geq t$ and using the law of conditional probability, the equations becomes;

$$\begin{aligned} \lambda(t) &= \lim_{dt \to 0} \frac{Pr\{t \leq T < t + dt\}/Pr\{T > t\}}{dt} \\ &= \lim_{dt \to 0} \frac{[F(t + dt) - F(t)]/\, dt}{S(t)} \\ &= \frac{\partial F(t)/\partial t}{S(t)} \\ &= \frac{f(t)}{S(t)} \end{aligned} \qquad (3.30)$$

where *f(t)* is the probability density function of *T* evaluated at *t*, the derivative or slope of the cumulative distribution function $1 - S(t)$. The hazard function can also be expressed as,

$$\lambda(t) = -\frac{\delta log S(t)}{\delta t}, \qquad (3.31)$$

which is the negative of the slope of the log of the survival function. The cumulative hazard function $\Lambda(t)$ is the sum of the individual hazard rates from time zero to time *T*. The formula for the cumulative hazard function is;

$$\int_0^t \lambda(v)\, dv = -logS(t) \qquad (3.32)$$

$$\Lambda(t) = -logS(t)$$

The cumulative hazard function is related to the cumulative survival function by the expression;

$$S(t) = exp[-\Lambda(t)] \qquad (3.33)$$

In order to capture the explanatory variables' effect on ARC entry λ(x), a Cox proportional hazard survival regression that allowed the hazard function λ(x) to be multiplied by exp(Xβ) was specified, where X denotes the vector of explanatory variables, (X_1, X_2, ..., X_k).

$$\lambda(t|X) = \lambda(t)exp(X\beta) \qquad (3.34)$$

By linearising this model with respect to ($X\beta$) to meet the survival model assumptions, the log hazard as a property of the T evaluated at time t allowed the distributional and regression effect to be investigated using the partial likelihood estimation method;

$$log\lambda(t|X) = log\lambda(t) + X\beta \qquad (3.35)$$

These regression effects (coefficients) for $X_j=\beta_j$, represented the increase in the log hazard at any fixed point in time if X_j is increased by one unit and all other explanatory variables were held constant as shown;

$$\beta j = log\lambda(t|X_1, X_2, \ldots, X_j + 1, X_{j+1}, \ldots, X_k) - log\lambda(t|X_1, \ldots, X_j, \ldots, X_k) \qquad (3.36)$$

This is equivalent to the log of the ratio of the hazards at time t. The log hazard $\lambda(t)$ is the baseline hazard function i.e the hazard function when all explanatory variables equal to zero. Alternatively, these effect values can be treated as the ratio of hazards at X_j + d versus X_j, all other explanatory variables held constant, is exp(β_jd). The effect of increasing X_j by d, was to increase the hazard of ARC entry by a factor of exp (βjd), at all points in time, with the assumption that X_j is linearly related to log$\lambda(t)$. Moreover, this model can be expressed in terms of the cumulative hazard and survival functions;

$$\begin{aligned} \Lambda(t|X) &= \Lambda(t)exp(X\beta), \\ S(t|X) &= exp[-\Lambda(t)exp(X\beta)] \\ &= exp[-\Lambda(t)]^{exp(X\beta)} \end{aligned} \qquad (3.37)$$

where $\Lambda(t)$ is the cumulative hazard function and $S(t|X)$,the probability of survival past time t given the values of the explanatory variables X, which can also be written as;

$$S(t|X) = S(t)^{exp(X\beta)} \qquad (3.38)$$

where $S(t)$ is the underlying survival distribution, $\exp(-\Lambda(t))$. The effect of the explanatory variables is by multiplying the hazard and cumulative hazard functions by a factor $\exp(X\beta)$, or the equivalently raising the survival function to a power equal to $\exp(X\beta)$.

3.4.5.3 Competing Risk Analysis.

Competing risks data occur when the interest is focused on a specific cause of failure in the presence of other different causes, which alter the probability of experiencing the event of interest (Kalbfleisch & Prentice, 2002). In this study, the event of interest after undergoing assessment is admission to ARC, however, there is the possibility of death occurring, hence, an individual may not have the opportunity to enter ARC. Death therefore, precludes the probability of experiencing ARC entry. This means that subjects who die after undergoing assessment are no longer at risk of ARC entry.

This situation contrasts with the classical setting of survival data where subjects are assumed to experience only one type of event. In the traditional survival setting, when there is only one type of event and individuals are followed until they experience it or are censored, an estimator of $P(T \leq t)$ can be obtained using the Kaplan-Meier method (Kaplan & Meier, 1958). However, for competing risk data, the use of Kaplan-Meier could lead to inconsistent estimators of the probability of experiencing the event in epidemiological research (Andersen, Geskus, de Witte, & Putter, 2012).

In a competing risk setting with k possible event types, the cumulative incidence for risk i is defined as $F_i(t) = P(T \leq t, R = i)$, where T denotes the random variable for the time to the first event and R is a random variable specifying the event type that occurred ranging from 1to k. A non-parametric cumulative incidence estimator which accounts for competing events was proposed by Kalbfleisch and Prentice (Kalbfleisch & Prentice, 1980). This section set out the

method for estimating $F_i(t)$, the cumulative incidence function for risk i, using the non-parametric estimator described by Kalbfliesh and Prentice(1980).

Denoting the observed data in the study as N and for $i \in (1,...,N)$, the time-to- event and censoring variables for the i^{th} subject is denoted as (t_i,δ_i), where t_i is the time at which an event is observed or the observation is censored; $\delta_i = 1$ if the study outcome occurred, $\delta_i = 2$ if the competing event occurred, and $\delta_i = 0$ if the event was censored. Let M denote the number of unique event-times when subjects failed from either cause, where $M = t_1 < t_2 < ... < t_j < ... < t_M$ be the unique observed times at which at least a failure occurs.

For $j \in \{1, \cdots M\}$, and $j \in \{1, \cdots N\}$, let $d_{1i}(t_j) = 1$ if subject i fails at time t_j of the study outcome and $d_{1i}(t_j) = 0$ otherwise; $d_{2i}(t_j) = 1$ if subject i fails at time t_j of the competing risk and $d_{2i}(t_j) = 0$ otherwise; $n_i(t_j) = 1$ if subject i is still at risk at (or immediately before) time t_j and $n_i(t_j) = 0$ otherwise.

At time t_j, the number of failures from the study outcome is $d_{1j} = \sum_{i=1}^{N} d_{1i}(t_j)$, the number of failures from the competing risk is $d_{2j} = \sum_{i=1}^{N} d_{2i}(t_j)$, the number of failures of any type at any type at time t_j is $dj = d_{1j} + d_{2j}$; and the number of individuals still at risk is $n_j = \sum_{i=1}^{N} d_i(t_j)$.

Therefore, in a competing risks setting, the cumulative incidence function for the study outcome is defined as $F_i(t) = P(T \leq t, R = i)$, where T is a random variable for the time to the first event and R is a discrete random variable specifying the type of event that occurred. $R = 1$ denotes the event of interest occurred, and $R = 2$ denotes the competing event occurred, the cumulative incidence function may be written in terms of the subhazards of the study outcome and competing risk (denoted $\lambda_1(t)$ and $\lambda_2(t)$ respectively). For $i = 1, 2$, the sub hazard for risk i, the instantaneous event rate, is defined as:

$$\lambda_1(t) = \lim_{\Delta \to 0} \frac{P[t \leq T < t + \Delta \mid T \geq t, R = i]}{\Delta} \qquad (3.39)$$

The overall survival function, that is, the probability of being event free from any cause, can then be written as:

$$S(t) = exp[-\int_0^1 (\lambda_1(v) + \lambda_2(v))\, dv] \qquad (3.40)$$

And the cumulative incidence function of the event of interest is:

$$F_1(t) = \int_0^1 \lambda_1(u)S(u)\,du \qquad (3.41)$$

Klein and Andersen (2005) note that the cause specific hazard and the cumulative incidence function require no assumptions about the dependence structure of the competing risks and that both can be estimated from the observed data. As shown in equation (3.41) the cumulative incidence can be written in terms of $S(t)$, the event-free probability of survival, and $\lambda_1 1(t)$ the subhazard of risk 1, so an estimator for the cumulative incidence is given by an estimator for each function based on the derivations done by Aalen (1978) and Pintelle (2006) and substituting these estimators into equation (3.41) gives the following estimator for the cumulative incidence for the first competing risk:

$$\hat{F}_1(t_j) = \sum_{p=1}^{j} \frac{d_{1p}}{n_p} \hat{S}(t_p - 1) \qquad (3.42)$$

where,

$$\hat{S}(t_j) = \prod_{p=1}^{j} (1 - \frac{d_{1p}+d_{2p}}{n_p}) \qquad (3.43)$$

This estimator is a non-parametric maximum likelihood estimator. Following the statistical analysis algorithm in competing risk analysis using R: an easy guide for clinicians, an add-on package for R statistical analysis (Scrucca, Santucci, & Aversa, 2007), an add-on R package, "cmprsk", was used to estimate the cumulative incidence of the risk of ARC entry when death is a competing risk across the functional decline status (ADL) of the COPD interRAI data where the probability of one type of competing event is correctly estimated using the Cumulative Incidence Function (CIF) which partitions the probability of failure into the probability of corresponding to each competing event (Klein, Rizzo, Zhang, & Keiding, 2001; Satagopan et al., 2004).

3.5 Ethical Approval

This study met all ethical requirements for the protection of human research participants in New Zealand. To ensure that the study was conducted on sound ethical principles, approval was obtained from the University of Canterbury Human Ethics Committee (HEC) based on the ethics approval to use interRAI data for research which was covered by the Ministry of Health's

Health and Disability Ethics Committee (14/STH/140) to the Health and Ageing research group (Appendix B) under the leadership of the principal investigator, Dr Hamish Jamieson of the Canterbury District Health Board (CDHB).

This approval cover projects that he co-supervises at the University of Canterbury including the work into outcomes in chronic obstructive pulmonary disease (COPD) of this thesis. This approval confirms the scientific soundness of the research without risk or misuse of the data approved. All participants had consented to the use of their information for planning and research with the assurance of personal information being removed as stated in the interRAI assessment home care assessment form (Appendix A, Section A question 9). Findings from the study have been sensitively reported using language that does not further disadvantage the participants. This approval confirmed independent ethical review of the research, and safeguarded the rights, health and well-being of the research participants.

Part of the data used for this research involved Māori as participants. Māori consultation was done through the Ngāi Tahu Consultation and Engagement Group of the University of Canterbury (see appendix C). Consultation with Māori is integral to ensuring that research proposals and projects are robust and transparent to the Māori community. The exchange of knowledge between researchers and the Māori community is of benefit to both parties and can improve research outcomes. Where Māori are included in research as participants, consultation ensures cultural oversight has been planned for, which will increase the likelihood that Māori will contribute to the project. Additionally, it strengthens the research, support the University's Strategy for Māori Development, and increase the likelihood of success with external engagement. It also increases the likelihood that the outcomes of research will be of benefit to Māori communities.

3.6 Summary

This chapter has explained how quantitative statistical methods were applied to the COPD interRAI data population subset to achieve the objectives of the study. The outcome and explanatory variables used in the study were described. Steps of univariate, bivariate and multivariable logistics regressions, how the risk stratification and as well as survival analysis were discussed. The results of the findings using these methods are presented in the next chapter.

CHAPTER FOUR

Results

This chapter set out the results of the analyses based on the objectives set out in Chapter 1. The goal of the thesis was to assess the role of functional decline as risk factor for ARC admission among community dwelling COPD elderly and on the basis of the identified risk factors, develop a risk stratification score. To this end, data from interRAI were obtained and analysed to derive these estimates. Specifically, the research objectives were to;

1. Test the hypothesis that those with better ADL capabilities were less likely to enter ARC after controlling for all other potential confounding variables.
2. Develop a risk stratification score based on the predictive ability of associated variables that contributed to ARC entry. The composite score characterises the 'Journey from an Independent to a Dependent Living Environment' and is given the acronym 'JIDE score'.
3. Assess the incremental risk of ARC entry based on the JIDE score.
4. Test the hypothesis that those with better ADL capabilities have reduced hazard of ARC entry after controlling for all other potential confounding variables.

The chapter is divided into five sections. In Section 4.1, the demographic and the disease related variables and their distribution in the study population are presented, along with a comparison between the study population as presented in the interRAI-HC and the population profile in terms of age, gender and ethnicity. This was done to examine the hypothesis that the study population is different from the general population of the same age groups who are not covered by the interRAI-HC.

In Section 4.2, the results of the bivariate analysis are presented. The study population was divided into those who were admitted to a residential care and those who were not admitted to the residential care unit. Comparative statistics including the chi-square tests for ordinal and nominal variables and the results of the unpaired t-tests for continuous variables along with mean and standard deviations were presented.

In Section 4.3, the results of the binary logistic regressions of the single variable models for the likelihood of admission into residential care are also presented. After dividing the

cohort data into two groups of training and testing data, the results of the iterative multivariable logistic regression (exploratory modelling) where the regression of the likelihood of entry into residential care units on the selected variables on the basis of the statistical and clinical significance are presented. This was done to build an explanatory model for admission to residential care units for those individuals with chronic obstructive pulmonary disease after adjusting for the effects of potential confounders.

In Section 4.4, the results are presented of the composite score obtained from the previous analyses. The composite score characterises the Journey from an Independent to a Dependent-living Environment and is given the acronym 'JIDE score'. After dividing the data set into training and testing samples, a single risk score for each individual was estimated. The continuously distributed treatment score was used to construct confusion matrices to estimate the sensitivity and specificity of specific cut-off points as the best risk stratification score for these individuals. The Receiver Operating Characteristic curve (ROC curve) and the relative areas under the curve (AUC) for the cut-offs are presented. The results of the best cut-off score that maximises the sensitivity and specificity of the predictive values are presented. Also, based on the constructed composite scores, a categorised incremental quartile risk regression distribution is also presented.

In Section 4.5, results of the time until the occurrence of an event of interest and the instantaneous risk of ARC entry based on the explanatory exposure variables of the final model of the multivariable Cox regression model and the Kaplan-Meier Curve are presented. Additionally, a non-parametric analysis of competing risk of ARC entry is also presented.

4.1 Description of the study population

Since 2012, all community care recipients in New Zealand have participated in a standardised assessment using the Home care International Residential Assessment Instrument (interRAI-HC). A comparison of distribution of the interRAI population 65 years and above and the national population of people 65 years and above based on the 2013 in New Zealand is presented below.

4.1.1 Comparison of interRAI and NZ Census.

Table 4.1 describes the comparison between the interRAI-HC cohort and the New Zealand 2013 census. The interRAI cohort is relatively older than the New Zealand population group. Female gender distribution is similar in both cohort. Ethnicity distribution is statistically significant.

Table 4.1: Comparison between interRAI and NZ Census (2013)

Variable	Category	interRAI (%)	NZ Census (%)	p-value
Age	≤ 69	6,487 (8.41)	196,020 (32.3)	<0.001
	70 - 79	20,141 (26.1)	256,672 (42.3)	
	≥80	50,499 (65.5)	84,344 (25.4)	
Gender	Male	30,054 (38.9)	278,874 (45.9)	0.13
	Female	47,073 (61.1)	328,158 (54.1)	
Ethnicity	Māori	4,411 (5.72)	32,181 (5.60)	<0.001
	Pasifika	2,424 (3.14)	13,944 (2.40)	
	Asian	1,765 (2.29)	27,312 (4.70)	
	European	67,960 (88.2)	516,306 (87.8)	
	Others	533 (0.69)	1,551 (0.30)	

4.1.2 COPD in the interRAI Population.

The health condition on which the study cohort was selected was Chronic Obstructive Pulmonary Disease (COPD). According to the interRAI-HC instrument through which the assessment was carried out, the disease diagnoses is the one the doctor has indicated is present and that affects a client's status, requires treatment, or symptoms management. Furthermore, it is described as being monitored by a home care professional or it was the reason for hospitalisation within the previous 90 days or since the last assessment, if assessment has been less than 90 days earlier.

The COPD cohort from the total interRAI data set was N=10,377. This group comprises those who had COPD as the primary diagnosis including those who were already receiving active treatment and/or those who were just being monitored but not receiving active treatment at the moment.

The minimum aged participant was 65 years while the oldest was 103 years. The average age of the study sample size i.e. all those who have been diagnosed with COPD and have undergone interRAI comprehensive assessment was 80.4 years (SD = 7.91). Furthermore, as shown in Table 4.2, the study population was characterised by more females than males. Almost half of the cohort had lost a partner i.e. they were widowed. Those who identified as Europeans comprised the highest ethnicity in the interRAI COPD cohort.

Table 4.2: Demographic profile of COPD interRAI cohort.

	Category	Frequency	Responses (%)
Age in years	Mean (SD)	80.4	(7.91)
Gender	Male	4,665	45.0
	Female	5,712	55.0
Relationship status	Never	418	4.0
	Married	3,994	38.5
	Widowed	4,696	45.2
	Others	1,269	12.2
Ethnicity	Māori	1,113	10.7
	Pasifika	362	3.50
	Asian	119	1.10
	European	8,730	84.1
	Other	53	0.50

Table 4.3 showed that about half of the cohort were not living alone and up to two-thirds did not consider themselves lonely. More than a quarter of the cohort have had at least one fall in the last 90 days. Additionally, Table 4.3 showed there was no greater decline or progressive loss in ADL performance among the cohort as more than half were independent i.e. they require no physical assistance, set up or supervision in any episode or minimal assistance or supervision was required. Almost half of the cohort have enough independent cognitive ability to make consistent, reasonable and safe decisions on a daily basis and about half had not visited the hospital in the previous 90 days. A minority of individuals transitioned to ARC.

Table 4.3: Distribution of other COPD interRAI cohort variables.

	Category	Frequency	Responses (%)
Living Arrangement	Alone	5,109	49.2
	With Someone	5,268	50.8
Loneliness	Not Lonely	8,105	78.1
	Lonely	2,272	21.9
Fall history	None (last 90days)	6,804	65.6
	At least one (last 90days)	3,573	34.4
Recent Hospitalisation	None within last 90 days	5,327	51.3
	31-90 days ago	1,959	18.9
	Currently in hospital	1,310	12.6
ADL	Independent	6,678	64.3
	Supervision	1,288	12.4
	Limited	1,083	10.4
	Extensive	692	6.70
	Maximal	263	2.50
	Dependent +	373	3.60
Cognition	Intact	4,709	45.4
	Borderline Intact	2,102	20.3
	Mild	2,693	25.9
	Moderate	620	6.00
	Severe +	253	2.40
ARC Entry	No ARC Entry	8,472	81.6
	ARC Entry	1,905	18.4

4.2 Explanatory variables association with ARC

The outcome variable in the study, transition to ARC, is expressed as a binary variable. The binary options were those who were admitted to residential care and those who were not.

Table 4.4: Demographic variables association with ARC entry likelihood

Variable	Category	Not Entered (%)	Entered ARC (%)	p-value
Age in years	Mean (SD)	79.9 (7.95)	82.6 (7.53)	<0.001
Age	≤ 69	899 (90.4)	95 (9.60)	<0.001
	70 - 79	2,521 (85.7)	419 (14.3)	
	80-89	3,425 (79.3)	892 (20.7)	
	≥90	806 (72.8)	301 (27.2)	
Gender	Male	3,785 (81.1)	880 (18.9)	0.23
	Female	4,687 (82.1)	1,025 (17.9)	
Ethnicity	Māori	994 (89.3)	119 (10.7)	<0.001
	Pasifika	338 (93.4)	24 (6.63)	
	Asian	97 (81.5)	22 (18.5)	
	European	6,994 (80.1)	1,736 (19.9)	
	Others	49 (92.5)	4 (7.55)	
Relationship	Never married	337 (80.6)	81 (19.4)	<0.001
	Married	3,316 (83.0)	678 (17.0)	
	Widowed	3,752 (79.9)	944 (20.1)	
	Others	1,067 (84.1)	202 (15.9)	

Table 4.4 indicates that the mean age for those who were admitted into ARC is higher than those who were not. The table indicates that there is a statistically significant difference in the distribution of the age between those who were admitted in ARC and those who were not ($p<0.001$), with a higher proportion of the older age groups admitted into ARC. The table indicates that there is a statistically significant difference in the distribution of the age group between those who were admitted in ARC and those who were not ($p<0.001$) with age groups above 80 years accounting for more ARC admissions. In regards to gender, there is no significant difference by gender between those who have had assessment and either moved into residential care or otherwise. However, slightly more men went into ARC (19% vs 18%, $p = 0.23$). More widowed elderly were admitted into ARC and the table indicates that there is a statistically significant difference in the distribution of relationship status between those who were admitted in ARC and those who were not ($p<0.001$). As shown in Table 4.4, a higher proportion of Europeans and Asians were admitted into ARC compared with other ethnic

groups. The table indicates that there is a statistically significant difference in ethnicity between those who were admitted in ARC and those who were not ($p<0.001$).

Table 4.5 indicates a higher percentage of the elderly who lived alone were admitted into ARC (20% vs 16%), of people who lived with someone ($p<0.001$). The table indicates that there is a statistically significant difference in the distribution of the living arrangement i.e. whether a person is living alone or with someone and entry into ARC. Living with someone includes immediate family members, spouse or partner only, living with a spouse or partner and others, living with a child (not spouse or partner), living with parents or guardians, with siblings, other relatives and non-relatives. A higher percentage of the elderly who have reported being lonely were admitted into ARC compared with those who were not (21% vs 18%, $p<0.001$). Table 4.5 indicates that there is a statistically significant difference in the distribution of expressed loneliness and admission to ARC. There is a statistical significant difference in the distribution of the cognitive ability between those who remained and those who transitioned into residential care, ($p <0.001$). More of those who went into ARC had moderate cognitive ability.

Table 4.5 also indicates that there is a statistical significant difference in the ADL performance ability between those who remained and those who transitioned into residential care ($p <0.001$). A greater proportion of elderly who require supervision whether limited, extensive or maximal support, to carry out Activities of Daily Living moved into ARC. As indicated in Table 4.5, both the mean IADL capacity score and the mean of the IADL performance score for those who entered ARC are higher than for those who did not. Both were statistically significant at $p<0.001$. Additionally, the table indicates that the mean depression rating score for those who were admitted into ARC is higher than those who were not. In contrast, the table indicates that the mean pain score for those who were admitted into ARC is lower than those who were not. Both are statistically significant at $p<0.001$. There is also a statistically significant difference in bladder continence between those who remained and those who transitioned into residential care, $p<0.001$. A lower proportion of elderly who had complete control of their bladder entered ARC.

Table 4.5: Non-demographic variables association with ARC entry likelihood

Variable	Category	Not Entered (%)	Entered (%)	p-value
IADL Capacity	Mean (SD)	23.2 (12.4)	27.1 (11.7)	<0.001
IADL Performance	Mean (SD)	3.7 (12.6)	27.4 (11.9)	<0.001
Depression	Mean (SD)	0.98 (1.72)	1.19 (1.98)	<0.001
Pain	Mean (SD)	1.27 (1.17)	1.09 (1.15)	<0.001
Living arrangement	Alone	4,065 (79.6)	1,044 (20.4)	<0.001
	With Someone	4,407 (83.7)	861 (16.3)	
Loneliness	Not Lonely	6,673 (82.3)	1,432 (17.7)	<0.001
	Lonely	1,799 (79.1)	473 (20.8)	
Cognition	Intact	4,079 (86.6)	630 (13.4)	<0.001
	Borderline	5,377 (82.7)	1,088 (16.8)	
	Mild	2,055 (76.3)	638 (23.7)	
	Moderate	421 (67.9)	199 (32.1)	
	Severe +	178 (70.4)	75 (29.6)	
Bladder continence	Continent	5,383 (83.2)	1,089 (16.8)	<0.001
	With cathetar	313 (79.4)	81 (20.6)	
	Infrequently	779 (80.6)	188 (19.4)	
	Occasionally	664 (77.9)	188 (22.1)	
	Frequently	1,143 (78.8)	308 (21.2)	
	Incontinent	190 (78.8)	51 (21.2)	
ADL	Independent	5,629 (82.3)	1,049 (15.7)	<0.001
	Supervision	965 (74.9)	323 (25.1)	
	Limited	838 (77.4)	245 (22.6)	
	Extensive	522 (75.4)	170 (24.6)	
	Maximal	200 (76.0)	63 (24.0)	
	Dependent +	318 (85.3)	55 (14.7)	

4.3 Explanatory Model Building

Following an epidemiological approach to explanatory model building, the data set was divided into training and testing groups. The training data set was used in an iterative multivariable logistic regression. In the first instance, selected variables were subjected to bivariate logistic regression.

4.3.1 Step 1: Bivariate Logistic Regression.

Bivariate logistic regression was carried out on selected variables that, using the training data set, were found to be associated with ARC entry. These variables were rank ordered in magnitude of the beta coefficients in absolute values to build various models as shown in Table 4.6, Table 4.7 and Table 4.8. ADL was always retained in the model as it was used to describe functional decline.

4.3.2 Step 2: Multivariable Logistic Regression.

Functional decline leading to ARC entry has been captured in the study using the variable ADL Hierarchy. The crude beta coefficient was 0.46 (OR, 1.58; 95% CI, 1.40-1.78).

As shown in Table 4.6, the model building commenced with fitting ethnicity to ADL hierarchy. There was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted beta coefficients of the two variables appeared close to the crude beta coefficients from their bivariate logistics regressions. This showed that they maintained a stronger position away from the null in their coefficient values. The addition of ethnicity as a variable into the model did not result in any remarkable changes. It was therefore retained in the model.

In Model 2 as shown in Table 4.6, the fitting of the fall history as an additional variable to those retained in the previous in Model 1 showed that there was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted beta coefficients of the variables appeared strong and relatively close to the crude beta values from their bivariate logistics regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

In Model 3 as shown in Table 4.6, the fitting of the last hospital stay as an additional variable to variables retained in the previous in Model 2 showed that there was a significant reduction

that was more than 20% in the coefficient magnitude of last hospital stay compared to its crude beta coefficient. This variable was dropped from the model building process.

In Model 4 as shown in Table 4.6, the fitting of an additional variable, Cognitive Performance Scale (CPS) score to the variables retained from model 3 showed that there was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted beta coefficients of the variables appeared strong and relatively close to the crude values from their bivariate logistics regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

In Model 5 as shown in Table 4.6, the fitting of an additional variable, loneliness, to the variables retained from model 4 showed that there was no significant reduction of up to 20% in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted coefficient values of the variables appeared strong and relatively close to the crude values from their bivariate logistics regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

Table 4.6: Results of Multivariable Models of Likelihood of ARC Entry.

Model	Variables	Coef.	Coef.*	OR (95% CI)	OR (95% CI)*
1	ADL	0.46	0.51	1.58 (1.40-1.78)	1.66 (1.47-1.88)
	Pasifika	-1.61	-1.75	0.20 (0.10-0.33)	0.17 (0.09-0.30)
	Māori	-0.82	-0.86	0.44 (0.34-0.55)	0.42 (0.33-0.54)
	Others	-0.78	-0.84	0.46 (0.24-0.78)	0.43 (0.23-0.74)
2	ADL	0.46	0.45	1.58 (1.40-1.78)	1.57 (1.39-1.78)
	Pasifika	-1.61	-1.72	0.20 (0.10-0.33)	0.18 (0.09-0.31)
	Māori	-0.82	-0.84	0.44 (0.34-0.55)	0.43 (0.33-0.55)
	Others	-0.78	-0.81	0.46 (0.24-0.78)	0.44 (0.24-0.76)
	Falls	0.43	0.35	1.54 (1.37-1.74)	1.42 (1.25-1.61)
3	ADL	0.46	0.43	1.58 (1.40-1.78)	1.54 (1.35-1.76)
	Pasifika	-1.61	-1.72	0.20 (0.10-0.33)	0.18 (0.09-0.31)
	Māori	-0.82	-0.84	0.44 (0.34-0.55)	0.43 (0.33-0.55)
	Others	-0.78	-0.81	0.46 (0.24-0.78)	0.45 (0.25-0.77)
	Falls	0.43	0.35	1.54 (1.37-1.74)	1.42 (1.25-1.61)
	Hospital (currently)	0.34	0.06	1.41 (1.19-1.68)	1.06 (0.88-1.28)
	Hospital (1-30days)	-0.01	-0.08	0.99 (0.84-1.17)	0.92 (0.78-1.09)
	Hospital (31-90days)	-0.07	-0.13	0.93 (0.79-1.10)	0.88 (0.74-1.04)
4	ADL	0.46	0.25	1.58 (1.40-1.78)	1.29 (1.13-1.47)
	Pasifika	-1.61	-1.83	0.20 (0.10-0.33)	0.16 (0.08-0.28)
	Māori	-0.82	-0.94	0.44 (0.34-0.55)	0.39 (0.30-0.50)
	Others	-0.78	-0.88	0.46 (0.24-0.78)	0.42 (0.22-0.72)
	Falls	0.43	0.29	1.54 (1.37-1.74)	1.33 (1.17-1.51)
	Cognition	0.27	0.26	1.31 (1.25-1.38)	1.30 (1.23-1.37)
5	ADL	0.46	0.27	1.58 (1.40-1.78)	1.30 (1.14-1.49)
	Pasifika	-1.61	-1.83	0.20 (0.10-0.33)	0.16 (0.08-0.28)
	Māori	-0.82	-0.94	0.44 (0.34-0.55)	0.39 (0.30-0.50)
	Others	-0.78	-0.88	0.46 (0.24-0.78)	0.42 (0.22-0.72)
	Falls	0.43	0.28	1.54 (1.37-1.74)	1.32 (1.16-1.50)
	Cognition	0.27	0.26	1.31 (1.25-1.38)	1.30 (1.23-1.37)
	Lonely	0.21	0.23	1.23 (1.07-1.41)	1.25 (1.09-1.44)

∗ Adjusted values

In Model 6 as shown in Table 4.7, the fitting of an additional variable, Pain Scale Score, to the variables retained from model 5 indicated that there was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted coefficient values of the variables appeared strong and relatively close to the crude values from their bivariate logistics regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

Model 7 in Table 4.7 showed the addition of gender to the retained variables in the preceding model. There was a sign change of the value of the coefficient of gender. This variable was dropped from the model building process.

In Model 8 as shown in Table 4.7, the fitting of the Depression Rating Scale Score as an additional variable to variables retained in the previous in Model 7 showed that there was a significant reduction that was more than 20% in the coefficient magnitude of Scale DRS compared to its bivariate beta coefficient. This variable was dropped from the model building process.

Model 9 in Table 4.8 showed the addition of bladder continence to the retained variables in the preceding model. There was a significant reduction that was more than 20% in the coefficient magnitude of bladder continence compared to its bivariate beta coefficient. This variable was dropped from the model building process.

Model 10 in Table 4.8 showed the addition of age to the retained variables in the preceding model. There was a significant reduction that was more than 20% in the coefficient magnitude of age compared to its bivariate beta coefficient. This variable was dropped from the model building process.

Table 4.7: Results of Multivariable Models of Likelihood of ARC Entry.

Model	Variables	Coef.	Coef.*	OR (95% CI)	OR (95% CI)*
6	ADL	0.46	0.27	1.58 (1.40-1.78)	1.30 (1.14-1.49)
	Pasifika	-1.61	-1.85	0.20 (0.10-0.33)	0.16 (0.08-0.27)
	Māori	-0.82	-0.94	0.44 (0.34-0.55)	0.39 (0.30-0.50)
	Others	-0.78	-0.91	0.46 (0.24-0.78)	0.40 (0.21-0.70)
	Falls	0.43	0.31	1.54 (1.37-1.74)	1.36 (1.20-1.54)
	Cognition	0.27	0.25	1.31 (1.25-1.38)	1.28 (1.21-1.35)
	Lonely	0.21	0.25	1.23 (1.07-1.41)	1.29 (1.12-1.49)
	Pain	0.21	-0.12	0.88 (0.84-0.93)	0.89 (0.84-0.94)
7	ADL	0.46	0.27	1.58 (1.40-1.78)	1.30 (1.14-1.49)
	Pasifika	-1.61	-1.85	0.20 (0.10-0.33)	0.16 (0.08-0.27)
	Māori	-0.82	-0.94	0.44 (0.34-0.55)	0.39 (0.30-0.50)
	Others	-0.78	-0.91	0.46 (0.24-0.78)	0.40 (0.21-0.70)
	Falls	0.43	0.31	1.54 (1.37-1.74)	1.36 (1.20-1.54)
	Cognition	0.27	0.25	1.31 (1.25-1.38)	1.28 (1.21-1.35)
	Lonely	0.21	0.25	1.23 (1.07-1.41)	1.29 (1.12-1.49)
	Pain	-0.13	-0.12	0.88 (0.84-0.93)	0.89 (0.84-0.94)
	Male	0.09	-0.02	1.09 (0.96-1.22)	0.98 (0.87-1.10)
8	ADL	0.46	0.27	1.58 (1.40-1.78)	1.30 (1.14-1.49)
	Pasifika	-1.61	-1.85	0.20 (0.10-0.33)	0.16 (0.08-0.27)
	Māori	-0.82	-0.94	0.44 (0.34-0.55)	0.39 (0.30-0.50)
	Others	-0.78	-0.91	0.46 (0.24-0.78)	0.40 (0.21-0.70)
	Falls	0.43	0.30	1.54 (1.37-1.74)	1.35 (1.19-1.53)
	Cognition	0.27	0.24	1.31 (1.25-1.38)	1.27 (1.20-1.34)
	Lonely	0.21	0.22	1.23 (1.07-1.41)	1.24 (1.07-1.44)
	Pain	-0.13	-0.13	0.88 (0.84-0.93)	0.88 (0.83-0.93)
	Depression	0.07	0.04	1.07 (1.05-1.11)	1.03 (1.00-1.07)

∗ Adjusted values

Table 4.8: Results of Multivariable Models of Likelihood of ARC Entry.

Model	Variables	Coef.	Coef.*	OR (95% CI)	OR (95% CI)*
9	ADL	0.46	0.27	1.58 (1.40-1.78)	1.30 (1.14-1.49)
	Pasifika	-1.61	-1.85	0.20 (0.10-0.33)	0.16 (0.08-0.27)
	Māori	-0.82	-0.94	0.44 (0.34-0.55)	0.39 (0.30-0.50)
	Others	-0.78	-0.91	0.46 (0.24-0.78)	0.40 (0.21-0.70)
	Falls	0.43	0.30	1.54 (1.37-1.74)	1.35 (1.19-1.53)
	Cognition	0.27	0.24	1.31 (1.25-1.38)	1.27 (1.20-1.34)
	Lonely	0.21	0.25	1.23 (1.07-1.41)	1.29 (1.12-1.48)
	Pain	-0.13	-0.12	0.88 (0.84-0.93)	0.89 (0.84-0.94)
	Bladder Continence	0.06	0.01	1.06 (1.02-1.10)	1.01 (0.98-1.05)
10	ADL	0.46	0.24	1.58 (1.40-1.78)	1.27 (1.11-1.45)
	Pasifika	-1.61	-1.76	0.20 (0.10-0.33)	0.17 (0.09-0.30)
	Māori	-0.82	-0.75	0.44 (0.34-0.55)	0.47 (0.36-0.61)
	Others	-0.78	-0.83	0.46 (0.24-0.78)	0.43 (0.23-0.75)
	Falls	0.43	0.29	1.54 (1.37-1.74)	1.33 (1.17-1.51)
	Cognition	0.27	0.23	1.31 (1.25-1.38)	1.26 (1.19-1.32)
	Lonely	0.21	0.26	1.23 (1.07-1.41)	1.30 (1.13-1.50)
	Pain	-0.13	-0.11	0.88 (0.84-0.93)	0.90 (0.85-0.95)
	Age	0.05	0.03	1.06 (1.02-1.10)	1.03 (1.02-1.04)
Final (6)	ADL	0.46	0.27	1.58 (1.40-1.78)	1.30 (1.14-1.49)
	Pasifika	- 1.61	-1.85	0.20 (0.10-0.33)	0.16 (0.08-0.27)
	Māori	-0.82	-0.94	0.44 (0.34-0.55)	0.39 (0.30-0.50)
	Others	-0.78	-0.91	0.46 (0.24-0.78)	0.40 (0.21-0.70)
	Falls	0.43	0.31	1.54 (1.37-1.74)	1.36 (1.20-1.54)
	Cognition	0.27	0.25	1.31 (1.25-1.38)	1.28 (1.21-1.35)
	Lonely	0.21	0.25	1.23 (1.07-1.41)	1.29 (1.12-1.49)
	Pain	0.21	-0.12	0.88 (0.84-0.93)	0.89 (0.84-0.94)

∗ Adjusted values

Model 6 is regarded as the CLOSE to FINAL model. Functional decline as captured with Activities of Daily Living (ADL) and after adjusting for ethnicity, history of falls, cognition, loneliness and pain frequency were the risk factors of the likelihood of ARC entry among those who have COPD.

4.4 JIDE Composite Score

Using the test data set (the 30% proportion of the COPD cohort) which was not part of the one used to build the model, the JIDE composite score for each observation in the testing data set was computed. In order to avoid the effect of the intercept when calculating the predictive score of each observation, known computer algorithms of predicting and classifying observations were not used. Alternatively, the computation was done by summing the product of the regression coefficient of each variable and their coded values/scores during the interRAI assessment. In order to capture these composite scores appropriately, variables with more than two factor levels were treated as stand-alone variables.

In the training data set, as shown in Figure 4.1, the average predicted probability for those who experienced ARC entry was 0.44 while the average predicted probability those who did not experience ARC entry was 0.13. The composite score ranges from -2.30 to 2.09 with a mean score of 0.18.

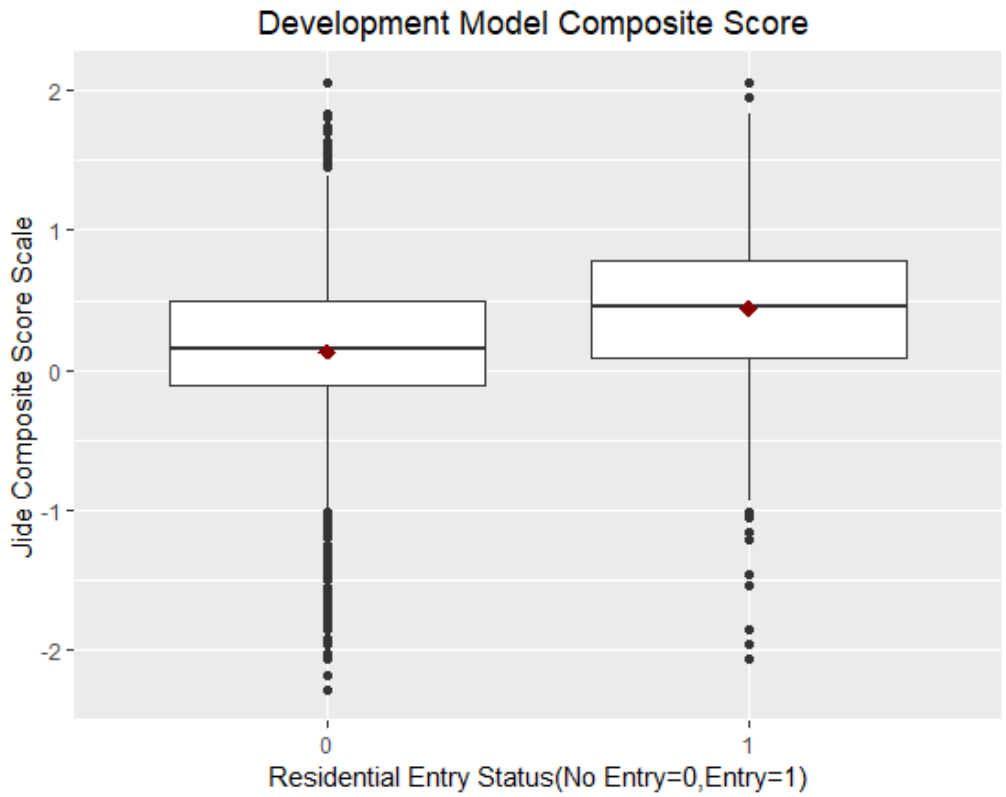

Figure 4.1: Training data model JIDE Composite Score

The AUC of the training model was 0.66 which indicated moderate predictive strength as shown in Figure 4.2.

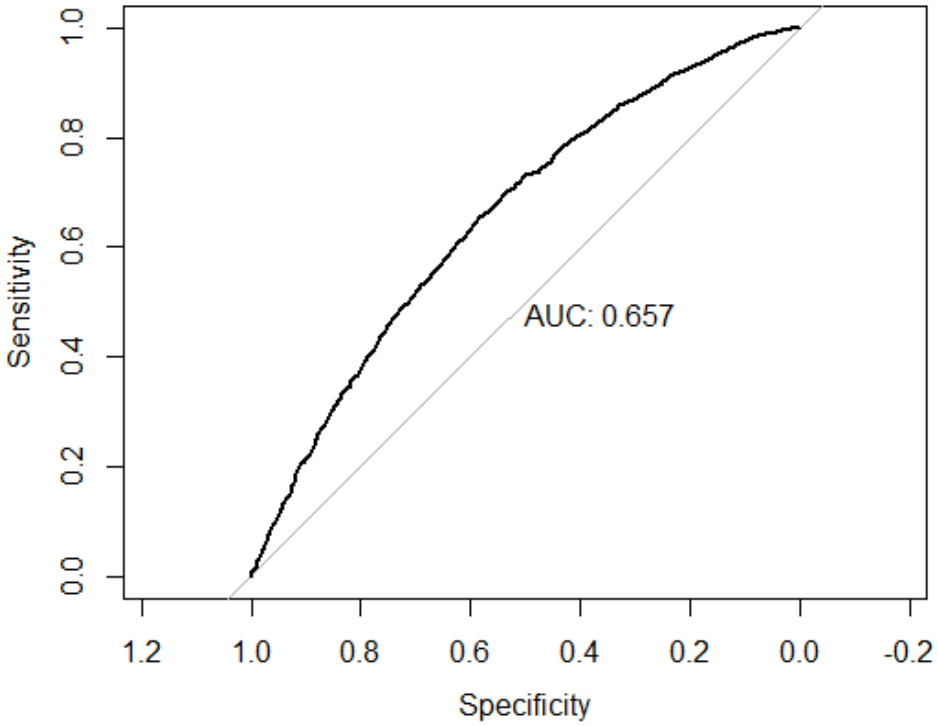

Figure 4.2: ROC of training model of ARC entry

In the test data set, the JIDE Composite score ranges from -2.09 to 2.04 with a mean score of 0.18. A summary of the composite score is shown in Table 4.9.

Table 4.9: The JIDE Composite Score.

Parameter	**Value**
Mean	0.18
25th Percentile	- 0.12
Median	0.24
75th Percentile	0.55
Maximum	2.06

The mean composite score for those who experienced ARC entry was 0.40 while it was 0.13 for those who were not admitted to ARC as shown in Figure 4.3

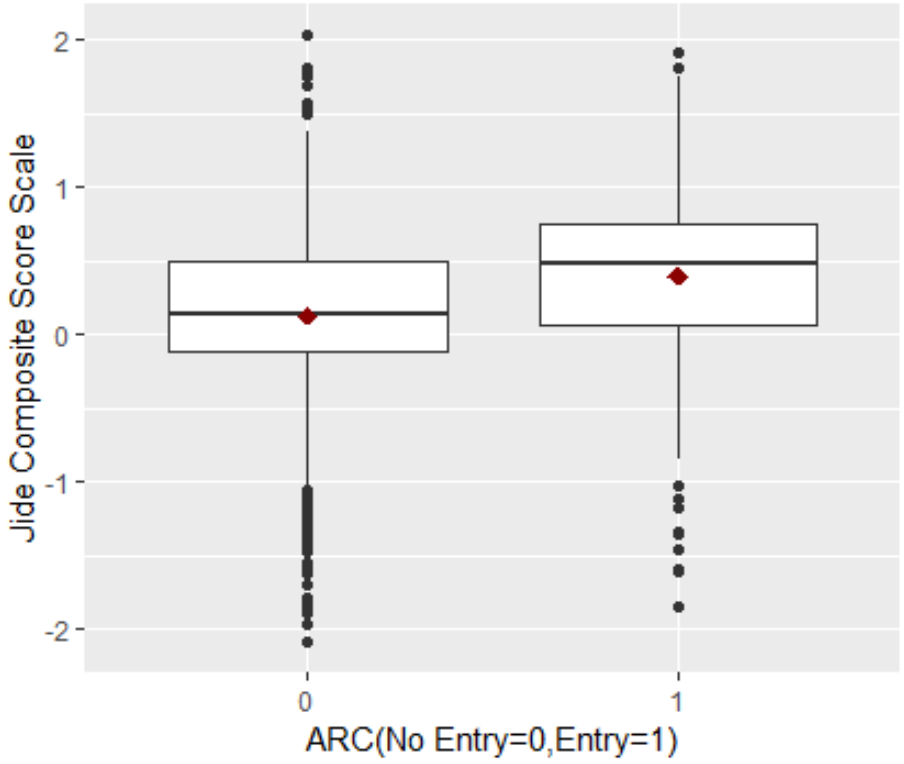

Figure 4.3: Mean value of the JIDE Composite score

The model discrimination was assessed using the receiver operating characteristic (ROC) curve in which the AUC value was 0.64 as presented in Figure 4.4. This indicated moderate predictive strength of the close to final model.

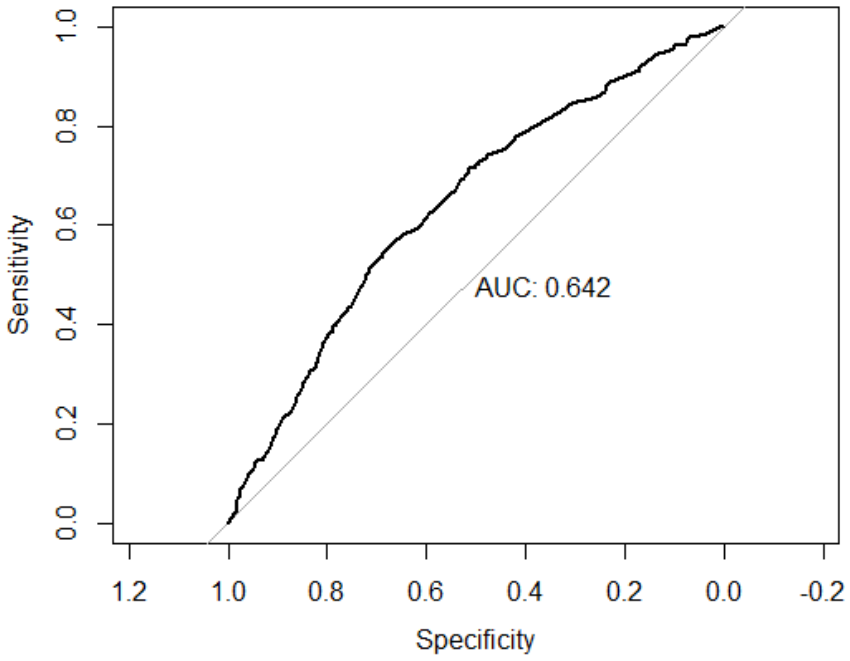

Figure 4.4: Likelihood of ARC entry model AUC curve.

The AUC of the testing model was 0.64 and close to the training model (0.66). Both indicated moderate predictive strength.

Other measures computed are presented in Table 4.10.

Table 4.10: The sensitivity, specificity, PPV and NPV for JIDE composite score

Predicted Value	interRAI Observed		Total
	Positive	Negative	
Positive	248	622	870
Negative	323	1,919	2,242
Total	571	2,541	
Composite Score Parameters	Percentage Value (%)		
Sensitivity	43.4		
Specificity	75.5		
Positive Predictive Value	28.5		
Negative Predictive Value	85.6		

4.4.1 Assessing increment of ARC entry risk categories.

For a better characterisation of the risk of ARC entry, the JIDE composite score was constructed into categorical levels. By dividing the composite score into quartiles, the lowest quartile ranges from -2.09 to -0.12 (this quartile was termed as "low"), the second quartile , termed "mild" ranges from -0.12 to 0.24, the third quartile termed "moderate", ranges from 0.24 to 0.54 while the fourth quartile termed "high", ranges from 0.54 to 2.04. A regression model shows how relative to the lowest quartile, there is progressive increment in the risk of ARC entry for subjects to the upper quartiles (Table 4.11).

Table 4.11: ARC Entry Incremental Risk

	Dependent variable:
	ARC Entry Incremental Risk Logistic Regression
Mild	1.34*** (0.99, 1.82)
Moderate	2.15*** (1.63, 2.87)
High	3.54*** (2.71, 4.66)
Observations	3,112
Log Likelihood	−1,396.23
Akaike Inf. Crit.	2,800.45
Note:	*p<0.1; **p<0.05; ***p<0.01

The second quartile (Mild Risk Level) has an odds ratio of 1.34 (95% CI, 0.99-1.82) compared to the lowest quartile-Low Risk Level (OR=1) shows that the risk of ARC entry minimally increased. The third quartile (Moderate Risk Level) with an odds ratio of 2.15 (95% CI,1.63-2.87) compared to the lowest quartile (OR=1) shows that the incremental risk of ARC admission is doubled for those whose ARC entry risk is moderate compared to those who have low risk. The fourth quartile (High Risk Level) with an odds ratio of 3.54 (95% CI,2.71-4.66) compared to the lowest quartile (OR=1) shows that the incremental risk of ARC admission is almost 4 times for those whose ARC entry risk is high compared to those who have low risk. Higher levels of the odds ratio of the JIDE composite scores are associated with higher risk of ARC entry.

4.5 Time to ARC entry

One of the major objective of the study is to assess the hazard (time to event) functional decline on ARC entry after undergoing interRAI assessment. As discussed in the methods section, a survival analysis is a branch of statistics that can be used to achieve such an outcome of time until the occurrence of an event of interest. The Kaplan-Meier Curve, Cox Proportional Hazard (PH) model and a non-parametric competing risk analysis were the methods used. The results are presented below.

4.5.1 Kaplan-Meier (K-M) Estimation

In order to estimate the K-M estimate, three elements were used. These were the duration time (survival time from time of assessment), status at duration time (1= Entry to ARC, 0=No entry to ARC), and group (1 = Entered ARC and 0= did not enter ARC).

Figure 4.5 and Table 4.12 showed the cumulative survival over a 3- year period of ARC entry within the study sample of elders who had an interRAI comprehensive assessment. The result suggested that ARC Entry cumulative survival was (75.0%) with a 95% CI (74-77%).

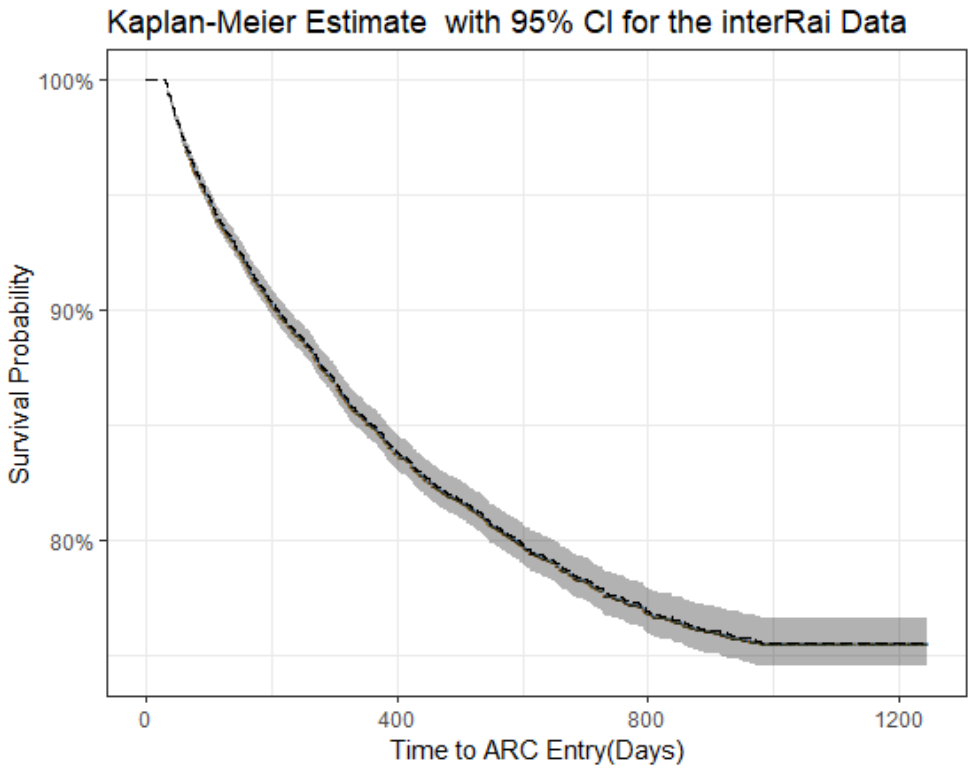

Figure 4.5: Overall Kaplan Meier

As shown in Figure 4.6 and Table 4.12, the results of the K-M analyses suggested that the unadjusted 3-year ARC entry survival probability was higher in the elderly who were independent in their ADL (78.0%) than in those who had limited-to-severe lack of independence in their ADL (71.0%), and that according to the log-rank test this difference was highly statistically significant ($p<0.001$).

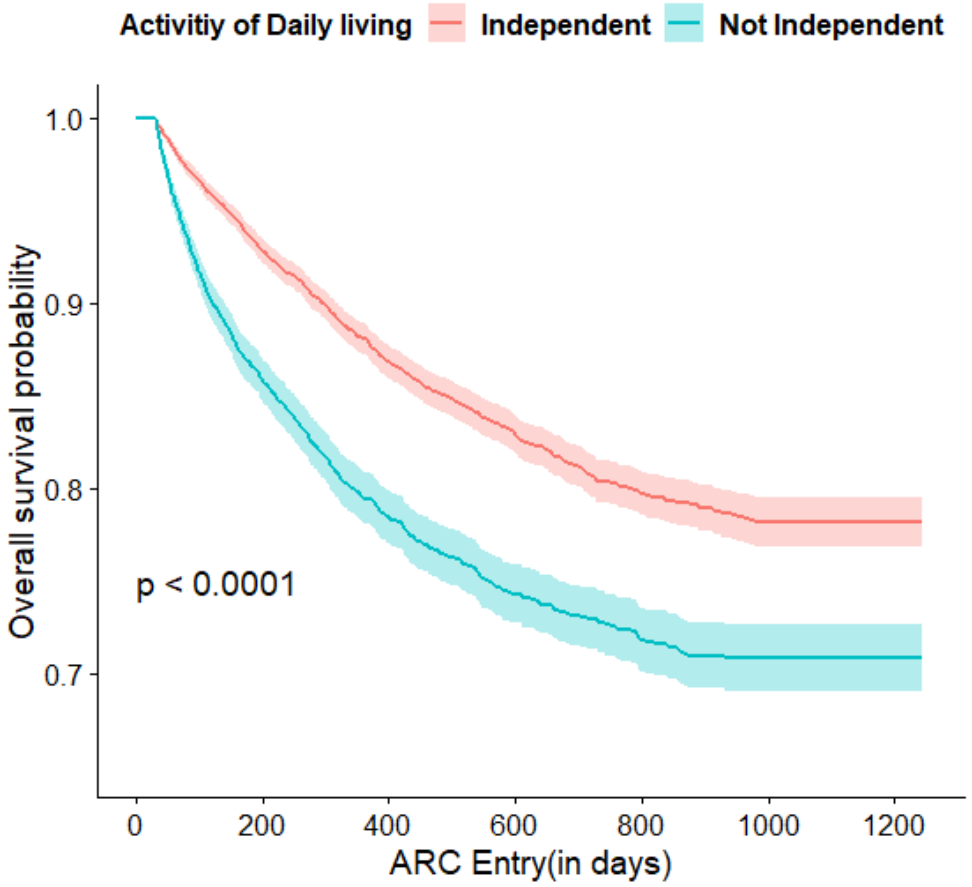

Figure 4.6: Activity of Daily Living Kaplan-Meier Curve

As shown in Figure 4.7 and Table 4.12, the results of the K-M analyses suggested that the unadjusted 3-year ARC entry probability was higher in the elderly who did not have any history of a fall in the previous 90 days (78.0%) than in those who had at least one fall in the last 90 days and that, according to the log-rank test, this difference was highly statistically significant ($p<0.001$).

The results of the K-M analyses as shown in Table 4.12, suggested that the un- adjusted 3-year ARC entry probability was higher in the elderly who lived with someone (78.0%) than in those who lived alone (73.0%), and that according to the log-rank test this difference was highly statistically significant ($p<0.001$) as shown in Figure 4.8.

Table 4.12: Kaplan-Meier Survival by explanatory variables

	3-year estimate (95% CI)
Overall	0.75 (0.74-0.77)
ADL	
Independent	0.78 (0.77-0.80)***
Not Independent	0.71 (0.69-0.73)
Age groups (in years)	
≤ 69	0.87 (0.85-0.89)***
70-79	0.81 (0.79-0.83)
80-89	0.72 (0.70-0.73)
≥ 90	0.63 (0.59-0.67)
Ethnicity	
European	0.74 (0.72-0.75)***
Others	0.78 (0.71-0.88)
Māori	0.85 (0.83-0.88)
Pasifika	0.92 (0.89-0.95)
Fall History	
None	0.78 (0.77-0.80)***
Yes	0.70 (0.68-0.72)
Living arrangement	
Alone	0.73 (0.72-0.75)***
With Someone	0.78 (0.77-0.79)
Cognition Score	
Intact	0.81 (0.80-0.83)***
Borderline Intact	0.77 (0.75-0.80)
Mild	0.68 (0.66-0.71)
Moderate-to-severe	0.61 (0.57-0.65)
Note: Log-rank test	*p<0.1; **p<0.05; ***p<0.01

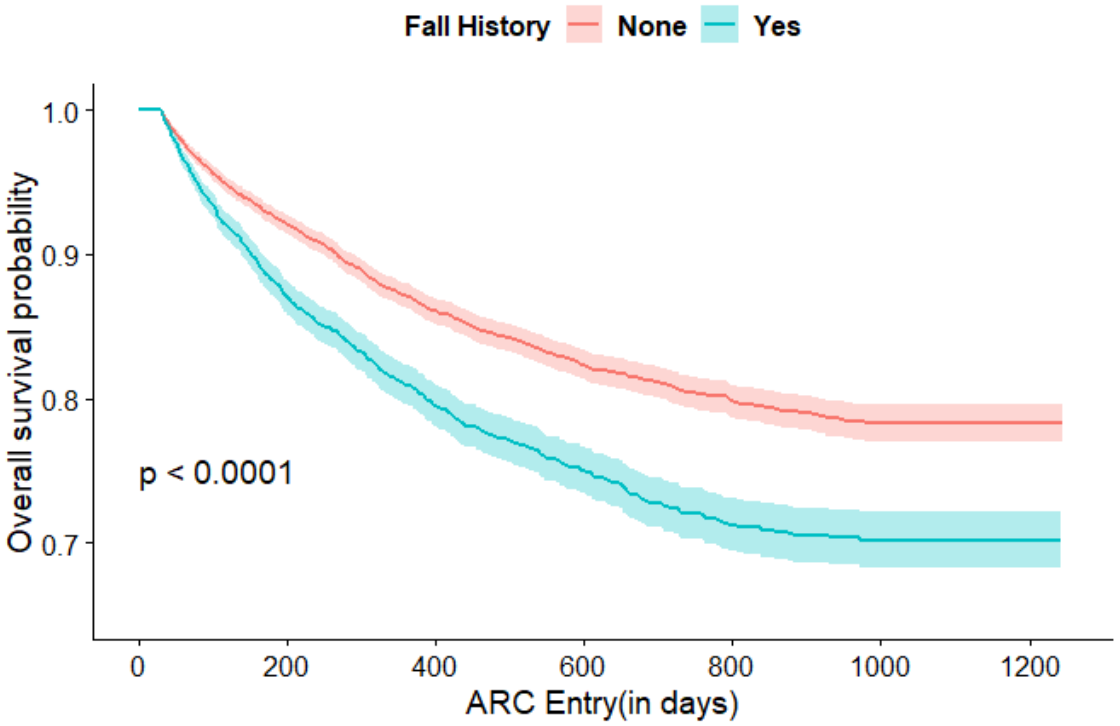

Figure 4.7: History of Fall Kaplan-Meier Curve

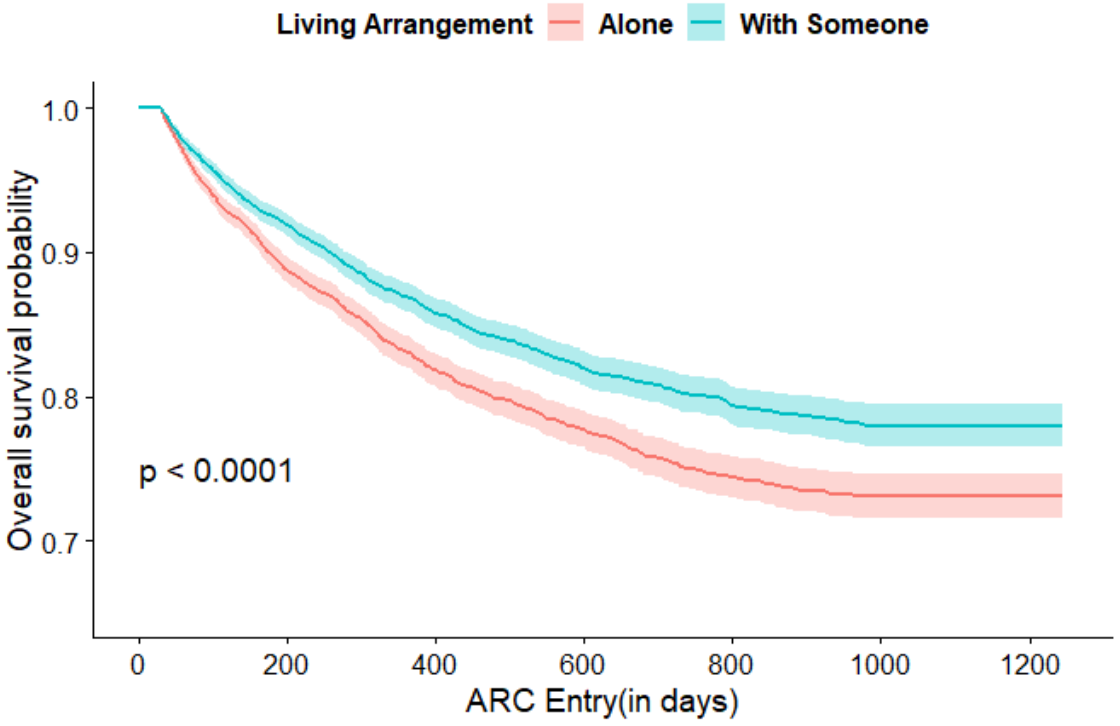

Figure 4.8: Living arrangement Kaplan-Meier Curve

The results of the K-M analyses as shown in Table 4.12, suggested that the un- adjusted 3-year ARC entry probability was higher in the elderly who lived with someone (78.0%) than in those who lived alone (73.0%), and that according to the log-rank test this difference was highly statistically significant (p<0.001) as shown in Figure 4.8.

As shown in Table 4.12, the results of the K-M analyses suggested that the unadjusted 3-year ARC entry probability was higher in the elderly who have intact/no impairment in their cognitive ability (81.0%) than in those who have a degree of impairment. The log-rank test of this difference was highly statistically significant (p<0.001). Figure 4.9 showed a progressive decrease in survival probability as the severity of impairment increases as confirmed by the highly statistically significant log-rank test (p<0.001).

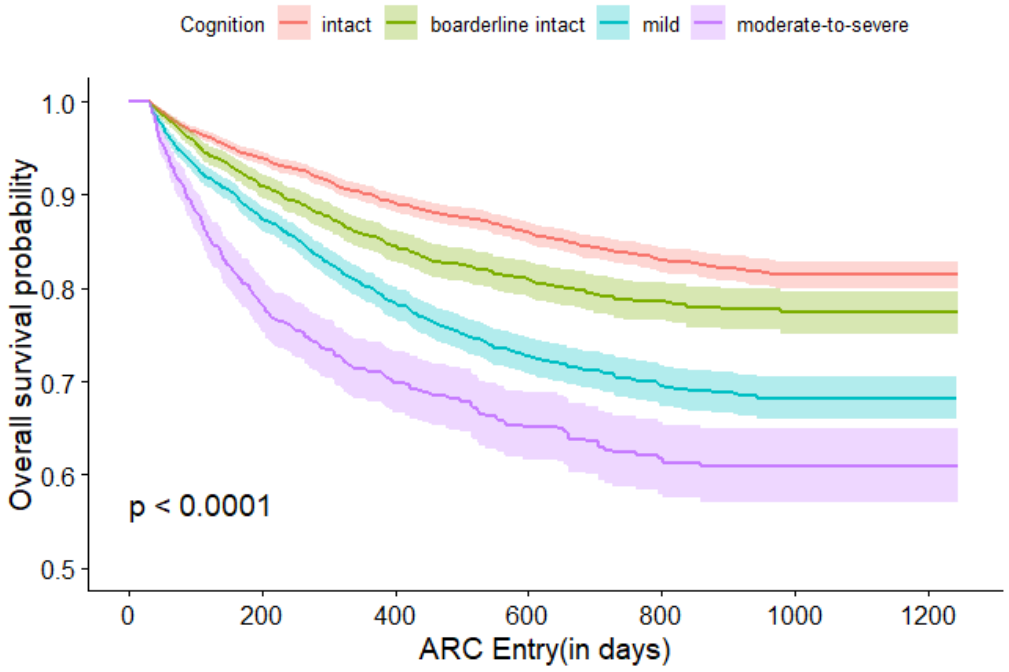

Figure 4.9: Cognition Kaplan-Meier

Table 4.12 showed that the unadjusted 3-year ARC entry probability differs among the various age groups of the elderly who have undergone an interRAI comprehensive assessment. Elderly who are above 90 years of age have the lowest ARC entry survival probability. The log-rank

test showed the difference was highly statistically significant ($p<0.001$) as shown in Figure 4.10.

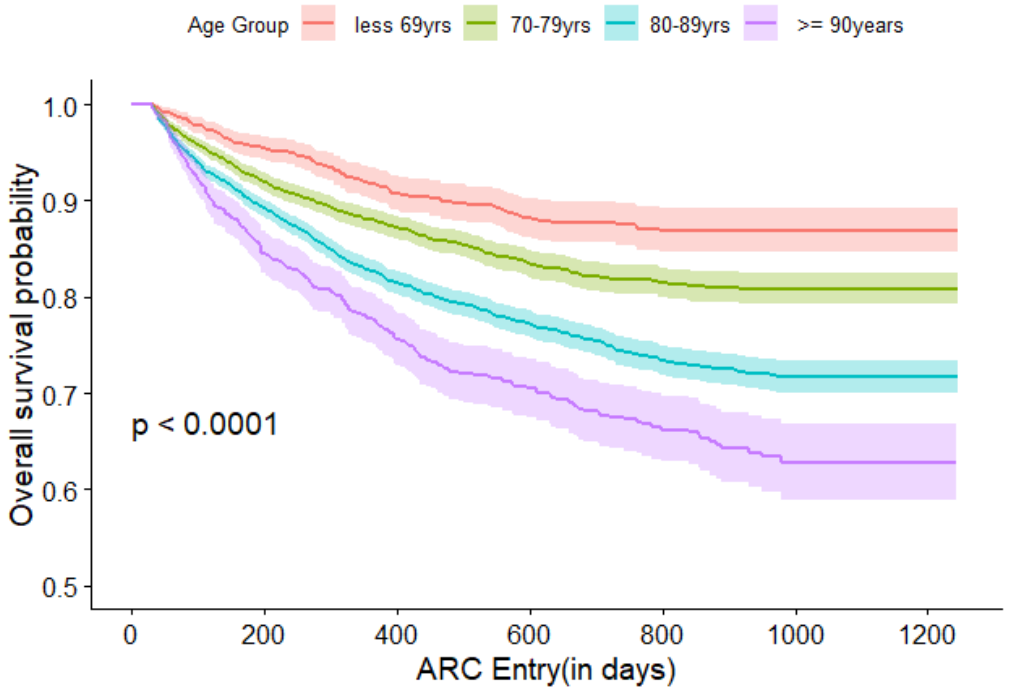

Figure 4.10: Age Group Kaplan-Meier

4.5.2 Cox Proportional Hazard Model.

4.5.2.1 Step 1: Bivariate Cox Regression : The outputs in Table 4.13, Table 4.14 and Table 4.15, show the regression beta coefficients, the effect sizes (given as hazard ratios) and statistical significance for each of the variables in relation to overall survival i.e. non-entry to ARC. Each factor was assessed through separate bivariate Cox regressions and the outputs represent the crude coefficient values or hazard ratios. These crude values were rank ordered with ADL as the base variable. The ranking order was as follows; ADL, ethnicity, hospital history, history of fall, cognition, loneliness, bladder continence, depression, gender and age.

ADL, fall history, cognitive score, loneliness, gender, depression, bladder continence and age have positive beta coefficients, while ethnicity and pain score have negative coefficients. Thus, ADL, fall history, cognitive score, loneliness, gender, depression, bladder continence and age are associated with poorer survival (i.e earlier ARC entry), whereas being Māori/Pasifika, low frequency of pain and not being in the hospital for more than 30days are associated with higher survival (i.e. they remain longer in the community). The output of hazard risks over time to ARC entry using the multivariable approach based on a Cox proportional hazard regression is presented below. The hazard of functional decline leading to ARC entry has been captured

in the study using the variable ADL Hierarchy. The crude beta coefficient was 0.47 with hazard ratio (HR, 1.60; 95% CI, 1.46-1.75)

4.5.2.2 Step 2: Multivariable Cox Regression

As shown in Table 4.13, the model building commenced with fitting Ethnicity to ADL hierarchy. There was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted beta coefficients of the two variables appeared close to the crude beta coefficients from their bivariate Cox regressions. This showed that they maintained a stronger position away from the null in their coefficient values. The addition of ethnicity as a variable into the model did not result in any remarkable changes. It was therefore retained in the model.

In Model 2 as shown in Table 4.13, the fitting of the last hospital stay as an additional variable to variables retained in the previous in Model 1 showed that there was a significant reduction that was more than 20% in the coefficient magnitude of last hospital stay compared to its crude beta coefficient. This variable was dropped from the model building process.

In Model 3 as shown in Table 4.13, the fitting of the fall history as an additional variable to those retained in the previous in Model 2 showed that there was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted beta coefficients of the variables appeared strong and relatively close to the crude beta values from their bivariate Cox regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

In Model 4 as shown in Table 4.13, by adjusting for an additional variable, Cognitive Performance Scale (CPS) score to the variables retained from model 3, there was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted beta coefficients of the variables appeared strong and relatively close to the crude values from their bivariate Cox regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

In Model 5 as shown in Table 4.13, by adjusting for an additional variable (loneliness) to the variables retained from model 4, there was no significant reduction of up to 20% in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted coefficient values of the variables appeared strong and relatively close to the crude values from their bivariate Cox regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

In Model 6 as shown in Table 4.14, by adjusting for an additional variable (Pain Scale Score) to the variables retained from model 5, there was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted coefficient values of the variables appeared strong and relatively close to the crude values from their bivariate Cox regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

Model 7 in Table 4.14 showed the addition of bladder continence to the retained variables in the preceding model. There was a significant reduction that was more than 20% in the coefficient magnitude of bladder continence compared to its bivariate beta coefficient. This variable was dropped from the model building process.

In Model 8 as shown in Table 4.14, the fitting of the Depression Rating Scale Score as an additional variable to variables retained in the previous in Model 7 showed that there was a significant reduction that was more than 20% in the coefficient magnitude of Scale DRS compared to its bivariate beta coefficient. This variable was dropped from the model building process.

Table 4.13: Results of Multivariable Models of Hazard of ARC Entry.

Model	Variables	Coef.	Coef.*	HR (95% CI)	HR (95% CI)*
1	ADL	0.61	0.67	1.85 (1.69-2.02)	1.95 (1.78-2.13)
	Pasifika	-1.24	-1.43	0.29 (0.19-0.43)	0.25 (0.17-0.38)
	Māori	-0.63	-0.67	0.51 (0.43-0.62)	0.49 (0.41-0.59)
	Others	-0.32	-0.44	0.73 (0.50-1.08)	0.68 (0.46-1.00)
2	ADL	0.47	0.48	1.60 (1.46-1.75)	1.61 (1.46-1.77)
	Pasifika	-1.23	-1.38	0.29 (0.20-0.44)	0.25 (0.17-0.38)
	Māori	-0.67	-0.70	0.51 (0.43-0.62)	0.50 (0.41-0.60)
	Others	-0.31	-0.39	0.73 (0.50-1.08)	0.68 (0.46-1.00)
	Hospital(currently)	0.44	0.24	1.56 (1.37-1.77)	1.28 (1.12-1.46)
	Hospital(1-30days)	0.01	-0.04	1.01 (0.86-1.14)	0.97 (0.85-1.10)
	Hospital(31-90days)	-0.06	-0.08	0.94 (0.83-1.07)	0.92 (0.82-1.05)
3	ADL	0.47	0.48	1.60 (1.46-1.75)	1.62 (1.48-1.77)
	Pasifika	-1.23	-1.34	0.29 (0.20-0.44)	0.26 (0.17-0.38)
	Māori	-0.67	-0.70	0.51 (0.43-0.62)	0.50 (0.41-0.60)
	Others	-0.31	-0.36	0.73 (0.50-1.08)	0.70 (0.47-1.03)
	Falls	0.41	0.33	1.51 (1.38-1.65)	1.39 (1.27-1.52)
4	ADL	0.47	0.28	1.60 (1.46-1.75)	1.32 (1.19-1.46)
	Pasifika	-1.23	-1.44	0.29 (0.20-0.44)	0.24 (0.16-0.35)
	Māori	-0.67	-0.77	0.51 (0.43-0.62)	0.46 (0.38-0.56)
	Others	-0.31	-0.41	0.73 (0.50-1.08)	0.67 (0.45-0.98)
	Falls	0.41	0.28	1.51 (1.38-1.65)	1.31 (1.20-1.44)
	Cognition	0.27	0.25	1.31 (1.27-1.35)	1.28 (1.24-1.32)
5	ADL	0.47	0.29	1.60 (1.46-1.75)	1.34 (1.22-1.48)
	Pasifika	-1.23	-1.44	0.29 (0.20-0.44)	0.24 (0.16-0.35)
	Māori	-0.67	-0.77	0.51 (0.43-0.62)	0.46 (0.38-0.56)
	Others	-0.31	-0.41	0.73 (0.50-1.08)	0.66 (0.45-0.97)
	Falls	0.41	0.27	1.51 (1.38-1.65)	1.31 (1.19-1.43)
	Cognition	0.27	0.25	1.31 (1.27-1.35)	1.28 (1.24-1.33)
	Lonely	0.21	0.23	1.23 (1.11-1.36)	1.27 (1.14-1.41)

∗ Adjusted values

Table 4.14: Results of Multivariable Models of Hazard of ARC Entry.

Model	Variables	Coef.	Coef.*	HR (95% CI)	HR (95% CI)*
6	ADL	0.47	0.29	1.60 (1.46-1.75)	1.34 (1.22-1.48)
	Pasifika	-1.23	-1.45	0.29 (0.20-0.44)	0.23 (0.16-0.35)
	Māori	-0.67	-0.78	0.51 (0.43-0.62)	0.46 (0.38-0.55)
	Others	-0.31	-0.43	0.73 (0.50-1.08)	0.65 (0.44-0.96)
	Falls	0.41	0.28	1.51 (1.38-1.65)	1.33 (1.21-1.46)
	Cognition	0.27	0.24	1.31 (1.27-1.35)	1.27 (1.22-1.32)
	Lonely	0.21	0.26	1.23 (1.11-1.36)	1.29 (1.17-1.44)
	Pain	-0.11	-0.10	0.90 (0.86-0.93)	0.91(0.87-0.95)
7	ADL	0.47	0.28	1.60 (1.46-1.75)	1.32 (1.20-1.46)
	Pasifika	-1.23	-1.46	0.29 (0.20-0.44)	0.23 (0.15-0.35)
	Māori	-0.67	-0.78	0.51 (0.43-0.62)	0.46 (0.38-0.55)
	Others	-0.31	-0.42	0.73 (0.50-1.08)	0.65 (0.44-0.96)
	Falls	0.41	0.28	1.51 (1.38-1.65)	1.32 (1.20-1.45)
	Cognition	0.27	0.23	1.31 (1.27-1.35)	1.26 (1.21-1.31)
	Lonely	0.21	0.26	1.23 (1.11-1.36)	1.29 (1.16-1.44)
	Pain	-0.11	-0.10	0.90 (0.86-0.93)	0.90 (0.87-0.94)
	Bladder Continence	0.08	0.03	1.08 (1.05-1.11)	1.03 (1.00-1.06)
8	ADL	0.47	0.29	1.60 (1.46-1.75)	1.34 (1.21-1.48)
	Pasifika	-1.23	-1.44	0.29 (0.20-0.44)	0.24 (0.16-0.35)
	Māori	-0.67	-0.78	0.51 (0.43-0.62)	0.46 (0.38-0.55)
	Others	-0.31	-0.43	0.73 (0.50-1.08)	0.65 (0.44-0.96)
	Falls	0.41	0.28	1.51 (1.38-1.65)	1.33 (1.21-1.46)
	Cognition	0.27	0.23	1.31 (1.27-1.35)	1.26 (1.22-1.31)
	Lonely	0.21	0.24	1.23 (1.11-1.36)	1.27 (1.14-1.41)
	Pain	-0.11	-0.10	0.90 (0.86-0.93)	0.90 (0.87-0.94)
	Depression	0.06	0.02	1.06 (1.04-1.09)	1.02 (0.99-1.04)

∗ Adjusted values

Model 9 in Table 4.15 showed the addition of gender to the retained variables in the preceding model. There was a sign change of the value of the coefficient of gender. This variable was dropped from the model building process.

Model 10 in Table 4.15 showed the addition of Age to the retained variables in the preceding model. There was no significant reduction (20%) in the coefficient magnitude and no change of the coefficient sign of the added variable. The adjusted coefficient values of the variables appeared strong and relatively close to the crude values from their bivariate Cox regressions. This showed that they maintained a stronger position away from the null in their coefficient values. All these variables were retained in the model building steps.

As the explanatory variable age was the last on the ranking order, Model 10 is regarded as the CLOSE to FINAL model.

Functional decline as captured with Activities of Daily Living (ADL) and after adjusting for ethnicity, history of falls, cognition, loneliness, pain frequency and age were the hazards to ARC entry among those who have COPD and have undergone interRAI first assessment. The hazard ratio represents the relative instantaneous risk of ARC entry over the follow up period.

Table 4.15: Results of Multivariable Models of Hazard of ARC Entry.

Model	Variables	Coef.	Coef.*	HR (95% CI)	HR (95% CI)*
9	ADL	0.47	0.30	1.60 (1.46-1.75)	1.34 (1.21-1.48)
	Pasifika	-1.23	-1.45	0.29 (0.20-0.44)	0.23 (0.16-0.35)
	Māori	-0.67	-0.79	0.51 (0.43-0.62)	0.45 (0.38-0.55)
	Others	-0.31	-0.42	0.73 (0.50-1.08)	0.65 (0.44-0.96)
	Falls	0.41	0.29	1.51 (1.38-1.65)	1.33 (1.22-1.46)
	Cognition	0.27	0.24	1.31 (1.27-1.35)	1.27 (1.22-1.32)
	Lonely	0.21	0.25	1.23 (1.11-1.36)	1.29 (1.16-1.43)
	Pain	-0.11	-0.10	0.90 (0.86-0.93)	0.91 (0.87-0.94)
	Gender	0.05	-0.07	1.05 (0.95-1.15)	0.93 (0.85-1.02)
10	ADL	0.47	0.27	1.60 (1.46-1.75)	1.31 (1.19-1.45)
	Pasifika	-1.23	-1.35	0.29 (0.20-0.44)	0.26 (0.17-0.39)
	Māori	-0.67	-0.59	0.51 (0.43-0.62)	0.55 (0.46-0.67)
	Others	-0.31	-0.38	0.73 (0.50-1.08)	0.69 (0.47-1.01)
	Falls	0.41	0.26	1.51 (1.38-1.65)	1.30 (1.19-1.43)
	Cognition	0.27	0.22	1.31 (1.27-1.35)	1.24 (1.20-1.29)
	Lonely	0.21	0.27	1.23 (1.11-1.36)	1.31 (1.18-1.45)
	Pain	-0.11	-0.08	0.90 (0.86-0.93)	0.92 (0.88-0.96)
	Age	0.04	0.03	1.04 (1.04-1.05)	1.03 (1.02-1.03)
Final	ADL	0.47	0.27	1.60 (1.46-1.75)	1.31 (1.19-1.45)
	Pasifika	-1.23	-1.35	0.29 (0.20-0.44)	0.26 (0.17-0.39)
	Māori	-0.67	-0.59	0.51 (0.43-0.62)	0.55 (0.46-0.67)
	Others	-0.31	-0.38	0.73 (0.50-1.08)	0.69 (0.47-1.01)
	Falls	0.41	0.26	1.51 (1.38-1.65)	1.30 (1.19-1.43)
	Cognition	0.27	0.22	1.31 (1.27-1.35)	1.24 (1.20-1.29)
	Lonely	0.21	0.27	1.23 (1.11-1.36)	1.31 (1.18-1.45)
	Pain	-0.11	-0.08	0.90 (0.86-0.93)	0.92 (0.88-0.96)
	Age	0.04	0.03	1.04 (1.04-1.05)	1.03 (1.02-1.03)

∗ Adjusted values

4.5.3 Competing Risk Analysis.

4.5.3.1 Cumulative Incidence Function

In order to estimate the probability for each competing event, a Cumulative Incidence Function (CIF) was used. The estimates were calculated using the duration time (survival time from time of assessment), the status where those censored (survivors), is coded as 0, 1 for those who entered ARC and 2 for those who died as shown in Table 4.16.

Table 4.16: Competing events category.

Status	N
Censored = 0	5,783
Entered ARC = 1	1,905
Died = 3	2,689

Treating death as a competing risk, the overall cumulative incidence for ARC entry was lower than that of death at every time point. The CIF of ARC entry was half that of death at 6 month from the time of undergoing interRAI assessment. The probability of entering ARC does not increase after the one and half years of undergoing interRAI assessment as shown in Table 4.17 and in the presented plot in Figure 4.11.

Table 4.17: Cumulative Incidence (and 95% Confidence Intervals) for ARC entry and Death over 3 year follow up at 6 monthly interval.

Time (in months)	**ARC Entry CIF (95% CI)**	**Death CIF (95% CI)**
6	0.07 (0.06-0.07)	0.13 (0.12-0.14)
12	0.14 (0.12-0.14)	0.20 (0.19-0.21)
18	0.20 (0.18-0.21)	0.25 (0.24-0.26)
24	0.24 (0.22-0.25)	0.29 (0.28-0.30)
30	0.24 (0.22-0.25)	0.33 (0.31-0.34)
36	0.24 (0.22-0.25)	0.37 (0.35-0.39)

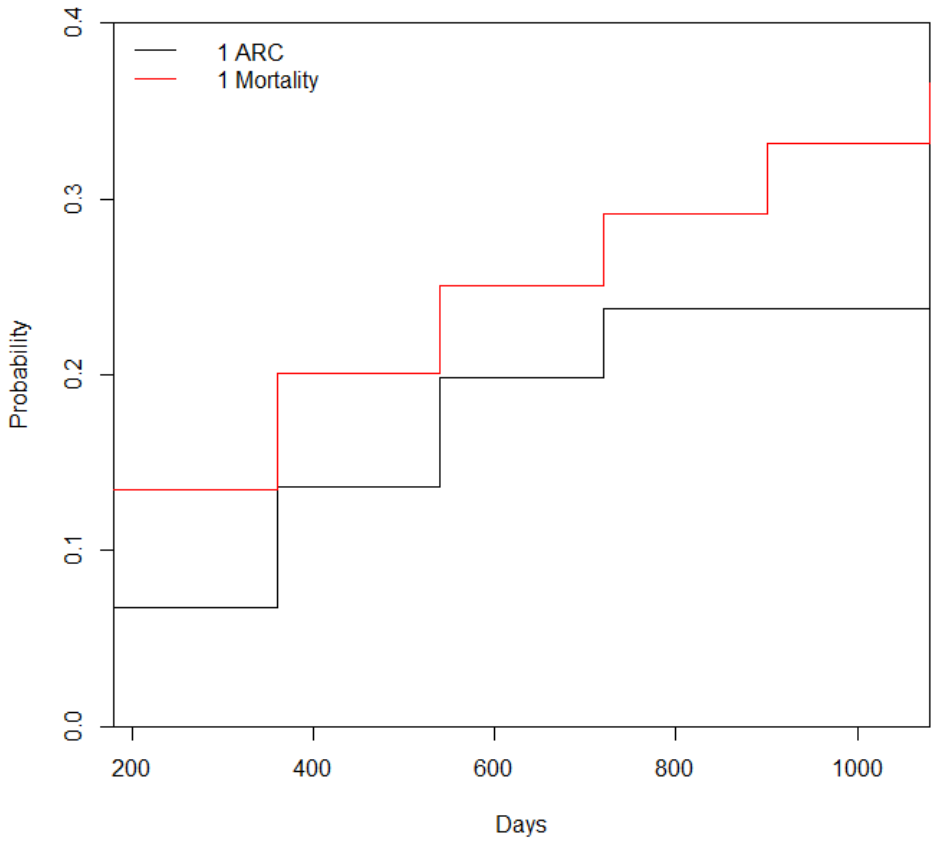

Figure 4.11: Estimated cumulative incidence function curves for competing events.

Individual plots of the cumulative incidence of the event of interest and the competing risk showing the confidence interval is presented in Figure 4.12.

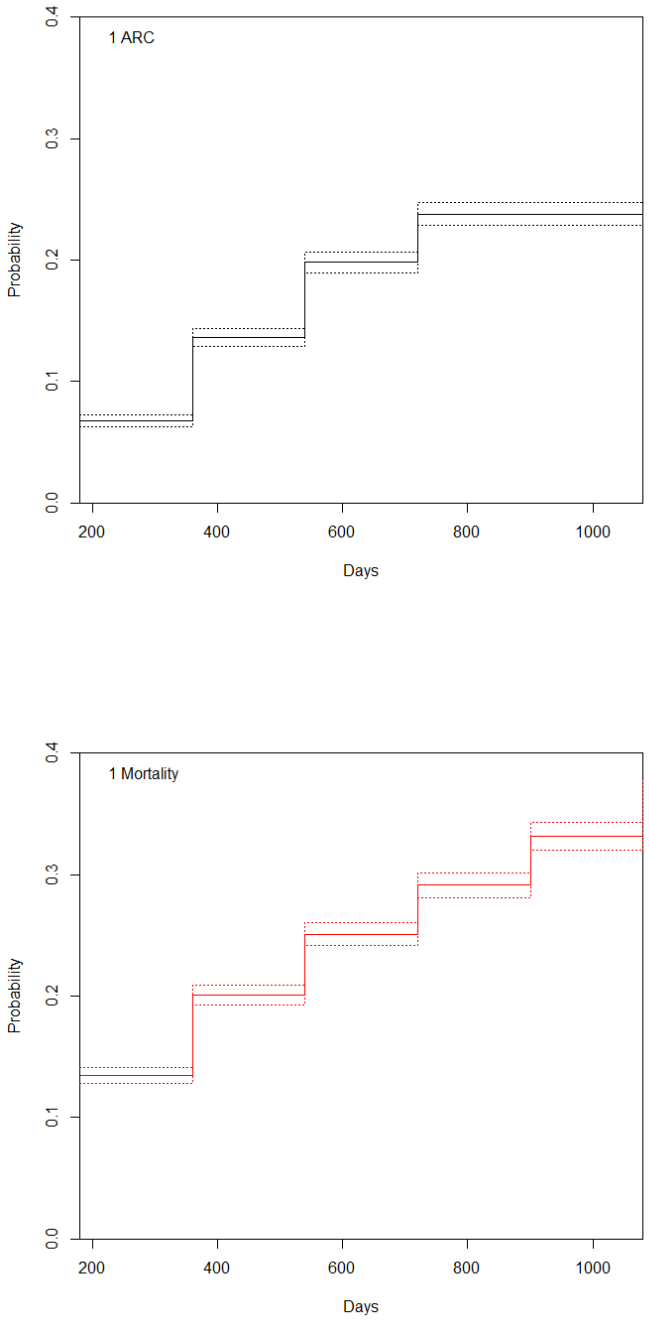

Figure 4.12: Estimated CIF curves for ARC Entry and Death with 95% CI

Using the main explanatory variable that captured functional decline, (Activity of Daily Living), the non-parametric competing risk analysis for ARC entry (the event of interest) and death (the competing event) are presented below. The cumulative incidence curves for those independent in their ADL and those dependent in their ADL are statistically different for those who went into ARC (coded as 1) and those who died (P-value=<0.001), as presented in the test Gray's test of equality across group (ARC entry=85.9 and Death=231.2). A plot of the estimated CIFs for each cause of event failure (ARC entry or death)-ADL status combination is presented in Figure 4.13.

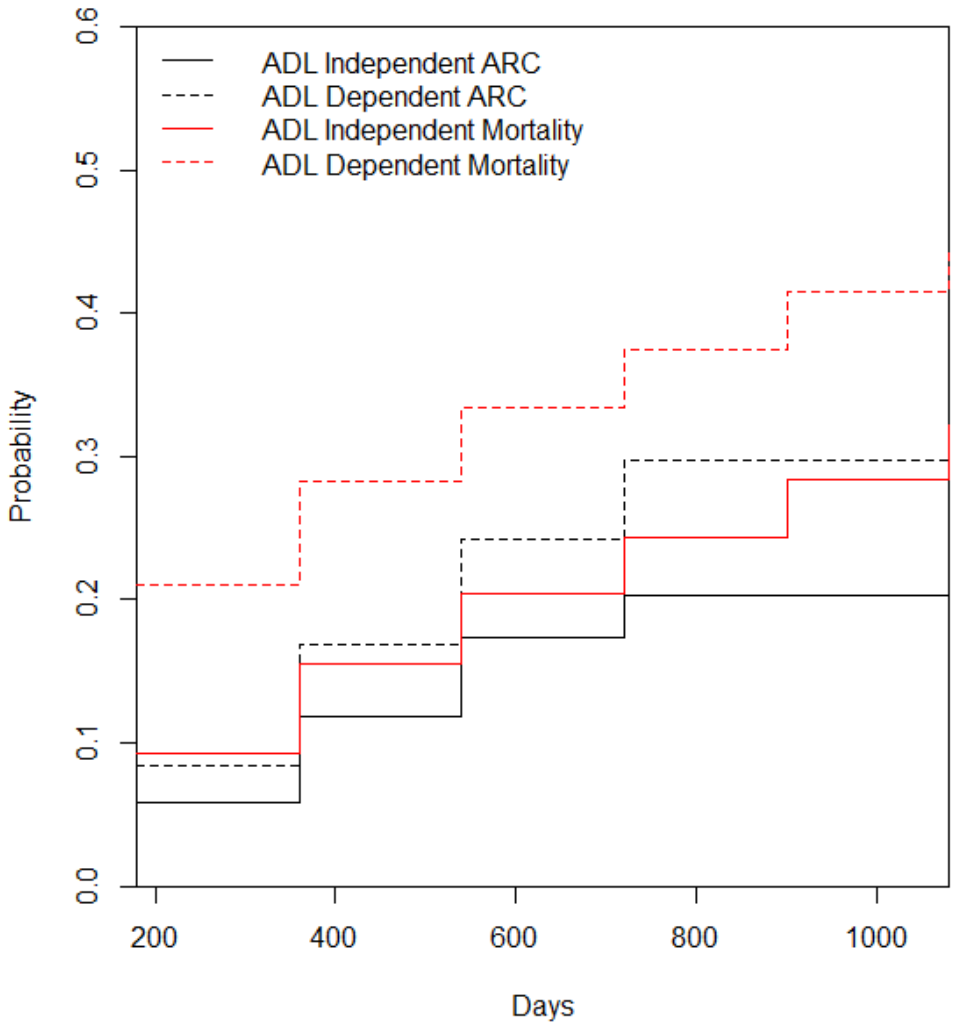

Figure 4.13: Estimated cumulative incidence curves with ARC entry(1) and death(2) as competing events for each category of ADL status(Independent or Dependent)

Table 4.18 shows the estimated CIF values with the corresponding confidence interval for any combination of competing events (ARC/Death) and ADL status (Independent/Dependent). The estimated lower and upper confidence limits at given time points (6-month interval) are reported in Figure 4.14, 4.15, 4.16 and 4.17.

Table 4.18: Estimated cumulative incidence curves with ARC entry (1) and death (2) as competing events for each category of ADL status (Independent or Dependent) with 95% CI at 6-monthly interval

Time	ARC Entry		Death	
	ADL Independent	ADL Dependent	ADL Independent	ADL Dependent
6	0.06 (0.05-0.06)	0.08 (0.07-0.09)	0.09 (0.08-0.10)	0.21 (0.19-0.22)
12	0.12 (0.11-0.13)	0.17 (0.15-0.18)	0.16 (0.14-0.16)	0.29 (0.26-0.30)
18	0.17 (0.16-0.18)	0.24 (0.23-0.26)	0.20 (0.19-0.22)	0.33 (0.31-0.35)
24	0.20 (0.19-0.21)	0.30 (0.28-0.31)	0.24 (0.23-0.26)	0.38 (0.36-0.39)
30	0.20 (0.19-0.21)	0.30 (0.28-0.31)	0.28 (0.27-0.30)	0.42 (0.39-0.43)
36	0.20 (0.19-0.21)	0.30 (0.28-0.31)	0.32 (0.30-0.34)	0.44 (0.42-0.46)

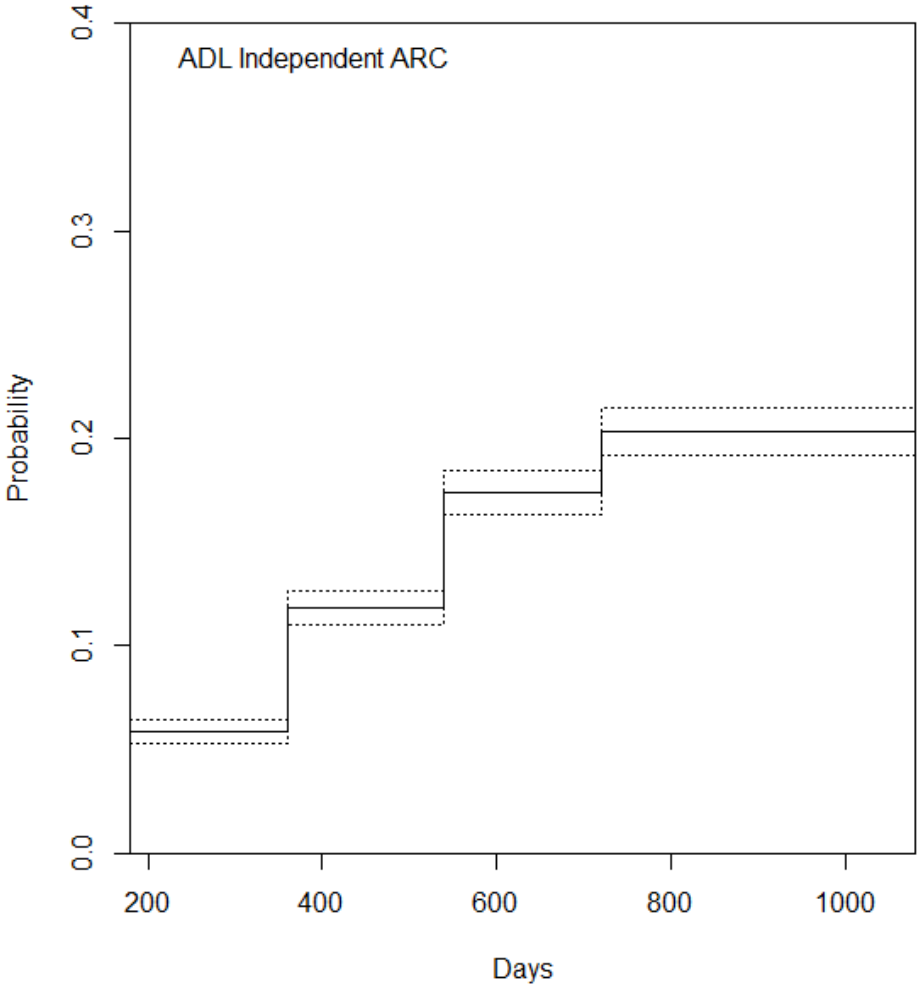

Figure 4.14: Estimated CIF curves(solid line) for each combination of competing events(ARC entry) and ADL status(Independent) with 95% pointwise Confidence Interval.

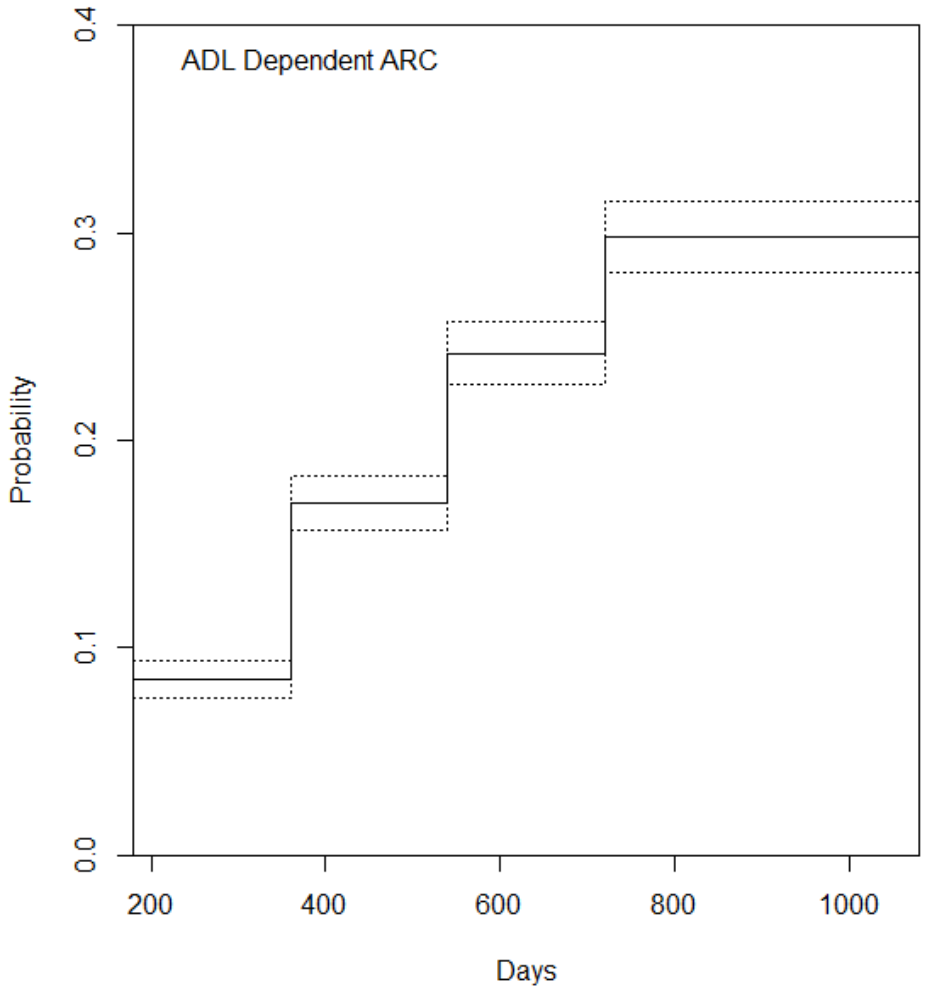

Figure 4.15: Estimated CIF curves (solid line) for each combination of competing events (ARC entry) and ADL status (Dependent) with 95% pointwise Confidence Interval.

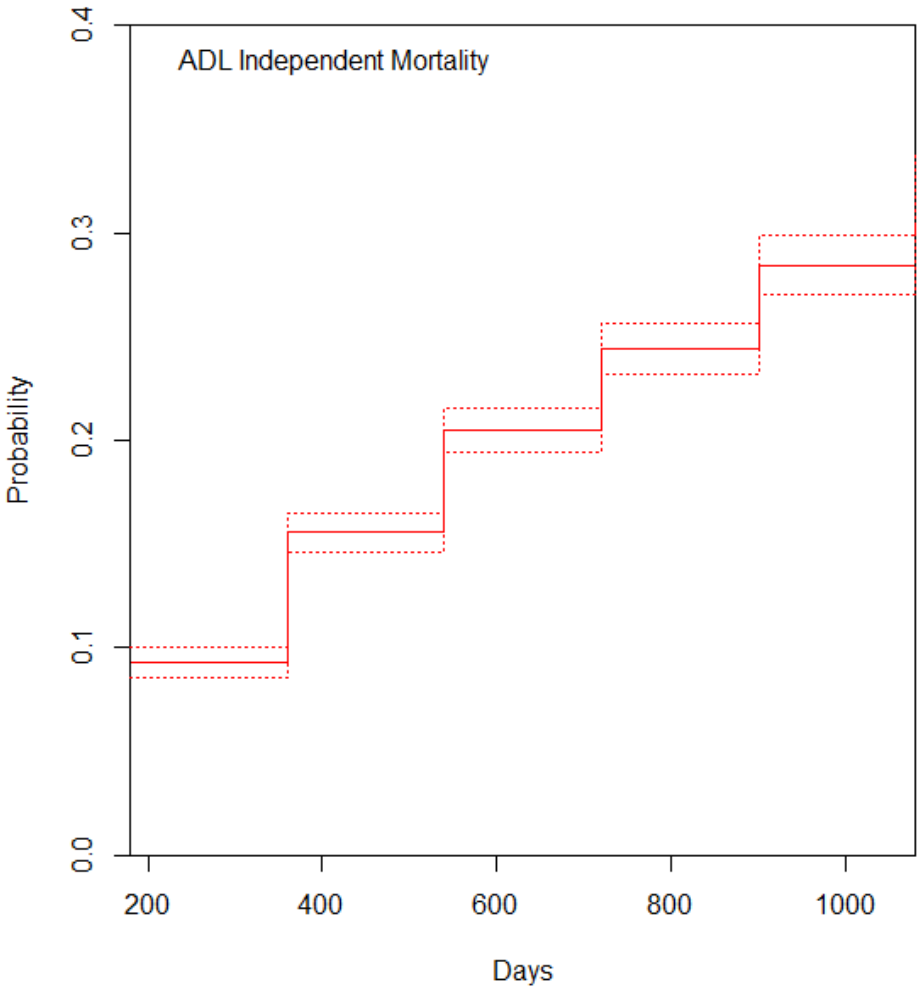

Figure 4.16: Estimated CIF curves (solid line) for each combination of competing events (Death) and ADL status (Independent) with 95% pointwise Confidence Interval.

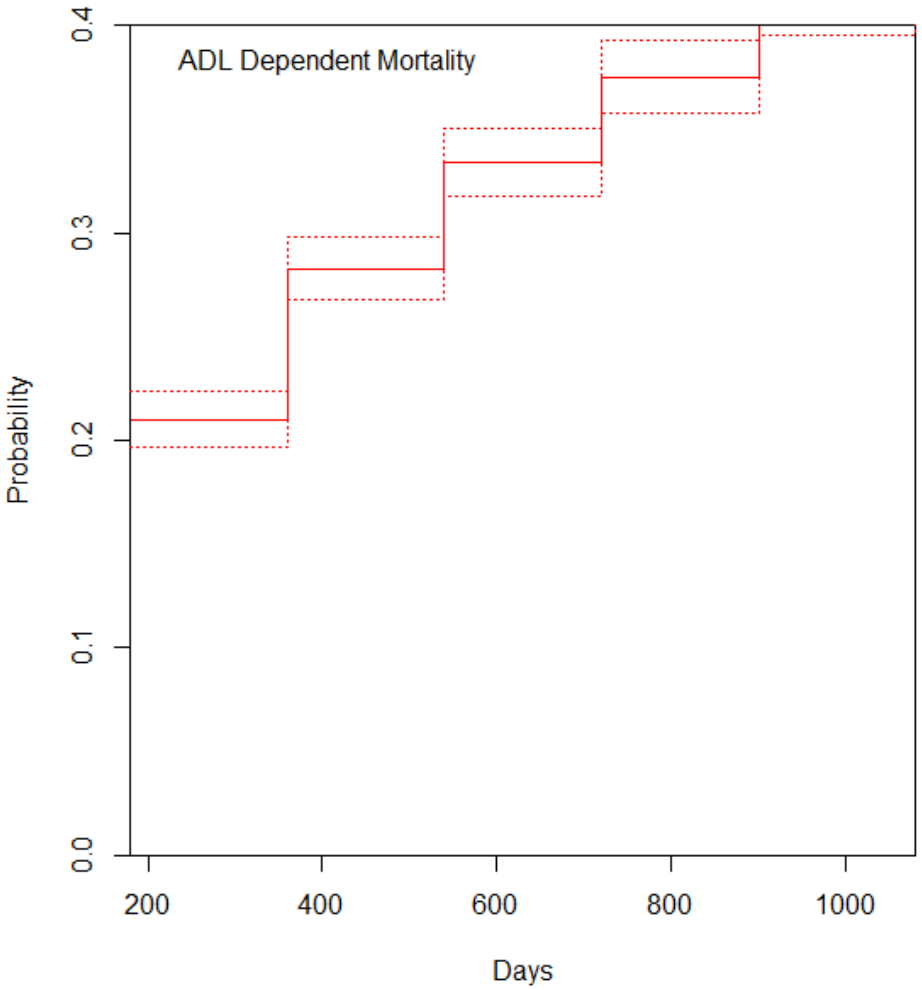

Figure 4.17: Estimated CIF curves (solid line) for each combination of competing events (Death) and ADL status (Dependent) with 95% pointwise Confidence Interval.

In chapter 5, the wider implications of the presented results in this chapter will be discussed in the light of the international literature.

CHAPTER FIVE

Discussion

The goal of the thesis was to assess the role of functional decline as risk factor for ARC admission among community-dwelling elderly with COPD. On the basis of the identified risk factors, a risk stratification score of entry to ARC for elderly people with confirmed diagnosis of COPD was developed. To achieve this goal, four research objectives were set;

1. Test the hypothesis that those with better ADL capabilities were less likely to enter ARC after controlling for all other potential confounding variables.
2. Develop a risk stratification score based on the predictive ability of associated variables that contributed to ARC entry. The composite score characterises the 'Journey from an Independent to a Dependent Living Environment' and is given the acronym 'JIDE score'.
3. Assess the incremental risk of ARC entry based on the JIDE score.
4. Test the hypothesis that those with better ADL capabilities have reduced hazard of ARC entry after controlling for all other potential confounding variables.

This chapter is arranged as follows. Section 5.1 presents a summary of the main findings of the study. Section 5.2 discusses the details the distribution of interRAI data population, national census and the interRAI COPD cohort and Section 5.3 discusses ARC entry within the interRAI COPD cohort. Section 5.4 sets out and discusses the impact of function decline in ADL on ARC entry for people with COPD after controlling for all other potential confounding variables. Based on the predictive power of these factors, the risk stratification score (JIDE) score is fully described and discussed in Section 5.5. The chapter also discusses the incremental risk of ARC entry for people with COPD based on categorised levels of the JIDE score. The hazard of transition to ARC and the competing risk of death as it affects functional decline are discussed in Section 5.6. A summary of the chapter is discussed in Section 5.7

5.1 Summary of main findings

High need individuals tend to be older and such people were the ones being presented for assessment as interRAI is designed to identify individuals with the greatest needs for

support and service delivery. The mean age for community-dwelling older adults in the interRAI COPD cohort was 80.4 years (SD=7.91)

The interRAI COPD population comprised 10% of the total interRAI population comprising more females (N = 5,712, 55% female). Close to half (45%) of the COPD interRAI cohort have lost a partner to death. There were more Europeans in the COPD interRAI cohort than other ethnic groups (N = 8,730, 84% European). Half of the interRAI COPD cohort live with someone (N = 5,268, 50.4%). Close to 35% of the COPD cohort have reported at least one fall in the last 90 days. Half of the COPD interRAI members reported no hospital stay in the last 90 days. Twenty two percent (N = 2,272) of the study cohort reported loneliness. In terms of activity of daily living, more than half (N = 6,678, 64%) of the COPD interRAI cohort were independent and almost half (N = 4,709, 45%) had intact cognitive capability.

At the end of the follow up period, 18% (N=1,905) of the COPD cohort had moved into ARC. After undergoing interRAI comprehensive assessment, more elderly stayed in the community/home rather than move into ARC (N=8,472, 82%). Those who did not transition into ARC were relatively younger than those who did. Most of those who transitioned to residential care identified as European.

The unadjusted impact of functional decline (ADL) and confounding variables associated with likelihood of ARC entry were estimated. Variables associated with an increased risk of entry to ARC in order of their effect size were: ADL (OR: 1.58, 95% CI: 1.40-1.78), History of fall (OR: 1.54, 95% CI: 1.37-1.74), Current Hospitalisation (OR: 1.41, 95% CI: 1.19-1.68), Cognition (OR: 1.31, 95% CI: 1.25-1.38), Loneliness (OR: 1.23, 95% CI: 1.07-1.41), Depression (OR: 1.07, 95% CI: 1.05-1.11), Bladder incontinence (OR: 1.06, 95% CI: 1.02-1.10) and Age (OR: 1.06, 95% CI: 1.02-1.10). Variables associated with a reduced risk of entry to ARC in order of their effect size were, Pasifika (OR: 0.20, 95% CI: 0.10-0.33), Māori (OR: 0.44, 95% CI: 0.34-0.55) and Pain (OR: 0.88, 95% CI: 0.84-0.93)

Assessing the impact of functional decline and while accounting for potential confounders, variables associated with an increased risk of entry to ARC in order of their effect size were: ADL (OR: 1.30, 95% CI: 1.14-1.49), History of fall (OR: 1.36, 95% CI: 1.20-1.54), Cognition (OR: 1.29, 95% CI: 1.21-1.35) and Loneliness (OR: 1.29, 95% CI: 1.21-1.35). Variables associated with a reduced risk (protective) for entry to ARC, arranged in order of their effect

size were; Pasifika ethnicity (OR: 0.16, 95% CI: 0.08-0.27), Māori ethnicity (OR: 0.39, 95% CI: 0.30-0.50) and Pain (OR: 0.89, 95% CI: 0.84-0.94).

Hazard of entry to ARC was defined as the likelihood of entry to ARC of an individual at a given point in time up to that point. Hazard ratios were estimated using Cox Proportional Hazards regression model using time to entry to ARC. Variables associated with increased hazard of entry to ARC arranged in order of their effect sizes were: ADL (HR: 1.60, 95% CI: 1.46-1.75), Current Hospitalisation (HR: 1.56, 95% CI: 1.37-1.77), History of fall (HR: 1.51, 95% CI: 1.38-65), Cognition (HR: 1.31, 95% CI: 1.27-1.35), Loneliness (HR: 1.23, 95% CI: 1.11-1.36), Bladder incontinence (HR: 1.08, 95% CI: 1.05-1.11), Depression (HR: 1.06, 95% CI: 1.04-1.09) and Age (HR: 1.04, 95% CI: 1.04-1.05). Variables associated with a reduced hazard of entry to ARC in order of their effect size were; Pasifika (HR: 0.29, 95% CI: 0.20-0.44), Māori (HR: 0.51, 95% CI: 0.43-0.62) and Pain (HR: 0.90, 95% CI: 0.86-0.93)

The hazard of entry to ARC based on functional decline when potential confounders were accounted for showed that variables associated with an increased hazard of entry to ARC in order of their effect size were; ADL (HR: 1.31, 95% CI: 1.19-1.45), History of fall (HR: 1.30, 95% CI: 1.19-1.43), Cognition (HR: 1.24, 95% CI: 1.20-1.29), Loneliness (HR: 1.31, 95% CI: 1.18-1.45) and Age (HR: 1.03, 95% CI: 1.02-1.03). Variables associated with a reduced hazard of entry to ARC in order of their effect size were; Pasifika ethnicity (HR: 0.26, 95% CI: 0.17-0.39), Māori ethnicity (HR: 0.55, 95% CI: 0.46-0.67) and Pain (HR: 0.92, 95% CI: 0.88-0.96).

Variables associated with likelihood of ARC entry from the logistic regression from the final model were combined to construct a composite score for the COPD cohort. The performance of the model was as follows: the sensitivity (43.4%), specificity (75.5%), and false positive rate (24.5%) while the AUC value was 0.64. The predictive strength of this score was moderate based on the Area under Curve (AUC). This score range was categorised into quartiles and labelled as low (lowest quartile), mild (second quartile), moderate (third quartile) and high (highest quartile). Higher levels of the odds ratio composite quartile category is associated with higher risk of ARC entry. The high group (OR: 3.54, 95% CI: 2.71-4.66) had almost four times as much risk of entering residential as the low group (OR: 1.0).

Death was a competing risk against entry to ARC. Event attributed to death (25%) was higher than that of the event of interest-ARC (18%). The non-parametric competing survival analysis

showed that COPD community-dwelling older adults who are dependent in their ADL are more likely to die than enter ARC.

5.2 Characterising interRAI and COPD cohort

There were differences in age distribution between those in the interRAI cohort and the national census. People were over-represented in the old-old age group (80 years and above) and under-represented in the interRAI for the young-old age group (65-69 years). This difference in proportions may be explained by the level of need. High need individuals tend to be older and such people were the ones being presented for assessment as interRAI is designed to identify individuals with the greatest needs for support and service delivery. This is consistent with other findings. Broad et al (2015) reported that at least 47% of New Zealanders use Residential Aged Care (RAC) after reaching the age of 65 years and most importantly, this rose to two-thirds of those aged over 85 years (Broad et al., 2015).

Within the interRAI, national census and the COPD cohort, there was no difference between the proportion of male and female. However, women were more likely to have an interRAI assessment than men. This is consistent with other research. The "Health of Older People in New Zealand" report published in 2002 states that, though there has been a narrowing trend of the gender gap among those over 65 years and above, by 2051 women will outnumber men and will comprise 61% of the elderly population (Fletcher & Lynn, 2002). Carpenter and Hirdes (2013) used data from nine OECD countries and regions to investigate how needs assessment data recorded at the point of care using the interRAI system can inform policy. Similar to our finding, the authors have reported that in home care and nursing home settings captured with interRAI instrument were a predominantly older, female population. The Northern Ireland Longitudinal Study (NILS) derived from the Northern Ireland Health Card registration system where 20,830 elderly over the age of 65 years were followed for a period of six years also found that women are 40% more likely to be admitted to ARC than men (McCann et al., 2012)

5.3 ARC entry within the COPD cohort

There is little or no specific research in New Zealand on the risk of ARC entry for COPD community-dwelling older adults when a change occurs in their ADL capacity after undergoing interRAI assessment. This is the first study in New Zealand to report interRAI assessment of COPD patients.

After undergoing interRAI comprehensive assessment, more elderly with COPD stayed in the community (or in their own home) than moved into ARC (82%). Those who remained in the community or home were relatively younger. Most of those who transitioned to residential care were Europeans (84%). The findings within the COPD cohort is consistent with Fletcher and Lynn (2002) report that within New Zealand, the point prevalence of people in residential care at is 6.3 percent (Fletcher & Lynn, 2002). Their findings also suggests that within developed countries, the overall point prevalence of older people in residential care is around 5 percent.

Broad et.al. (2011) have predicted the general trend of admission to ARC on the basis of four cross-sectional surveys conducted in Auckland, New Zealand in 1988, 1993, 1998, and 2008 over a 20-year period. They have reported that the proportion of older people living in residential aged care has fallen over the last 20 years in Auckland (1 in 13 to 1 in 18), particularly in ARC where age-specific rates halved (Broad et al., 2011). It is suggested that compulsory needs assessments for community dwelling older adults before entry using standardised assessment tool, availability of more options for home-based services, and market and policy changes such as the updated ageing strategy may have reduced utilisation. Along similar lines, Kendig et.al. (2010) have reported on the basis of a 10-year prospective study of 1,000 men and women aged 65 years and over to determine social and lifestyle factors of entry to ARC in Australia, that 42% remained living in the community while 5% moved into residential aged care (Kendig et al., 2010).

How older people with COPD understand the meaning of “ageing in place", may also underscore why there is a reduction in ARC entry in New Zealand. A qualitative study engaged older people, ranging in age from 56 to 92 years, in focus groups and interviews in two case studies. This was done in communities of similar sizes in New Zealand to explore the meaning of the concept of "ageing in place". The study found that older people want choices about where and how they age. They considered it an advantage in terms of a sense of attachment or connection and feelings of security and familiarity in relation to both homes and communities. They also regarded it as a sense of identity both through independence and autonomy and through caring relationships and roles in the places they prefer to live (Wiles, Leibing, Guberman, Reeve, & Allen, 2012).

Since interRAI assessment reports are collated nationally, and DHBs across the country manage the process of ARC entry for older adults, there are significant variations across DHBs

as to when people are admitted to aged residential care. Some reports have noted that it takes up to two months in certain regions across the country after undergoing assessment. Nationally, 41.2% of people were admitted to aged residential care during 2015/2016 within 12 months. However, the New Zealand Aged Care Association have reported that in some DHBs only 28% of people were admitted within that time (New Zealand Aged Care Association, 2017, 2018). This difference in time to ARC entry may represent different needs (including disease condition such as COPD management) around the country or it may indicate different responses (e.g. fewer ARC beds available; better access to home care).

A potential explanation why a low level of ARC entry (18%) among elderly with COPD has been noted in this study might be the severity of disability of older adults. Elderly adults who are not very frail or very chronically ill might not be considered, quite appropriately, for ARC entry. Many older adults in the COPD cohort were independent in their ADL (64%) and almost half (45%) had intact cognitive ability. Older people who transition to ARC may do so due to a chronic medical condition that results in permanent disability. An older study in the United Kingdom by Davies and Nolan (2006) argue that high ARC entry trends are usually increasing for frail people with highly specialised needs and high levels of cognitive impairment (Davies & Nolan, 2006). This is consistent with local data, as one in four (25%) among those who have undergone interRAI Home Care assessments in New Zealand were reported as having a dementia diagnosis (interRAI New Zealand, 2018e).

Low level of ARC may be attributable to the older person's choice and preferences, with many elderly people preferring to remain in their homes for as long as possible rather than to be institutionalised. By staying in their own homes, they are able to maintain the integrity of their social networks, preserve environmental landmarks, and enjoy a better quality of life. Also, there may be a cost burden of institutional care that creates reluctance on the part of older adults and their families for ARC entry. Good access to home care may also be a reason why more elderly choose to stay at home. In a recent study that discussed the trend of home as a health promoting setting for the older adults within the Nordic countries, it was reported that only by taking into consideration the meaning of home and the resources of the individual older person can home function as a true health promoting setting (Mahler et al., 2014).

5.4 Impact of factors contributing to ARC entry for people with COPD

Consistent with the previous studies, this study found that in all persons of 65 years of age and above who have been diagnosed with COPD, the risk of entry into residential care was associated with ADL as an independent risk factor after adjustment for ethnicity, history of fall, cognition, loneliness and pain frequency. The analyses of this study support the hypothesis that, for older persons, the change in functional capacity to perform ADL increases risk of entry to ARC, after controlling for ethnicity, history of fall, cognition, loneliness and pain frequency. The impact of these variables in determining the likelihood of ARC entry in the study were very high.

Studies have consistently shown that ADL is one of the predictors of ARC entry. Edemekong (2019) reported that an individual's inability to perform ADLs constitutes a disability that often requires further assessment, such as measurement of functionality which then becomes a significant predictor of being admitted into an assisted facility or ARC. The activities of daily living (ADLs) are essential and routine chores that individuals can achieve without the need for assistance. The six essential ADLs include the ability to be able to eat independently, dress, walk or transfer from one place to another, bath, use the bathroom for toileting, and maintain good continence. They are among the basic functions of everyday life and are central to our ability to comprehend the experience of the elderly who transitioned into residential care (Ikegami et al., 1997; Phillips et al., 1997).

In this study, there is a higher chance that lower capacity to carry out ADL results in the likelihood of ARC entry for older adults with COPD. Although, there are no available studies specifically on COPD samples and ARC entry, this outcome is consistent with the findings in the United States where it was found that the risk of admission increases with an increase in the number of limitations in activities of daily living (ADL) experienced by older people (Penrod, 2001; Gaugler, Duval, Anderson, & Kane, 2007b).

After adjusting for other factors especially cognition, the effect size contribution of ADL became less strong for people with COPD. The reduction in the effect size after adjusting for other variables such as cognition is entrenched in the fact that ADLs comprised different types of skills requiring sequencing of action, conceptual knowledge, and manipulation needed to achieve the intended goal. The ability to perform ADLs is dependent upon cognitive (e.g.,

reasoning, planning), motor (e.g., balance, dexterity), and perceptual (including sensory) abilities (Mlinac & Feng, 2016a; Bienkiewicz, Brandi, Goldenberg, Hughes, & Hermsdörfer, 2014). Therefore, when the cognitive capacity of an older person is maintained at mild-to moderate levels, ADL capacity is preserved (Jorgenson, 2007), which is also a similar explanation for the COPD cohort.

This study has shown that cognitive impairment predisposes an elderly person with COPD to changes in ADL levels leading to ARC entry. This outcome was also found among those who moved into residential care in the United States where those with moderate cognitive impairment experienced the greatest deterioration in early-loss and mid-loss ADL items (personal hygiene, dressing, toilet use) and those with severe cognitive impairment showed the greatest deterioration in activities related to eating, a late loss ADL (G. I. Carpenter, Hastie, Morris, Fries, & Ankri, 2006).

A possible explanation of the increased risk of ARC entry from the impact of ADL might be due to underlying chronic medical conditions such as COPD that has a subtle effect on ADL performance levels. For example, in New Zealand, it is known that 35% of home care clients with dementia require extensive assistance or are completely dependent in their ADLs. It is also known that, of those with chronic medical conditions affecting their cognitive performance who have undergone interRAI assessment, 18% receive full time care from family or friends for up to 40 hours per week (interRAI New Zealand, 2016). Such people are more likely to require help and support with activities such as bed mobility, transferring, walking, dressing, eating, toilet use, personal hygiene and bathing hence opting for the alternative to transition into a residential care where these services can be adequately provided.

Considering that functional decline among elderly with COPD was examined using the ADL-Hierarchy scale, the large effect size from the study showed that self-performance is on a continuum ranging from early loss, middle loss, to late loss (Morris et al., 1999). The large effect size of ADL leading to ARC entry is likely to begin with loss of ability to perform dressing and personal hygiene and gradually moving to the level where activities of eating and bed mobility becomes difficult for individuals to manage alone. Ample amount of research exist on the risk of ARC entry, however, it is noted that there are no available studies internationally that focused on ARC entry risk among COPD diagnosed older adults.

One of the confounding variables with a large effect size from this study is the history of falls. Falls are common among the elderly and are indicated as a common reason for ARC entry. This study confirmed that falls have a great effect size in explaining why older adults with COPD go into ARC. A general research reported that individuals who consistently report falls event are at an increased risk of ARC entry. In the United Kingdom, thirty percent of people over the age of 65 years who live in the community fall each year and this proportion increases to 50 percent by the age of 80 years (Tinetti et al., 1988). They concluded that falls among older persons living in the community are common and that a simple clinical assessment can identify the elderly persons who are at the greatest risk of falling.

A recent prospective, population-based 22-year follow-up study among 70 year olds living in the city of Turku, in the South-western of Finland examined the effect of predictive factors on institutionalisation (Salminen et al., 2017). The authors reported that among 1032 community dwelling older adults, the institutionalisation rate was 22%. Additionally, they reported having several falls during the periods year was found to be a factor that accelerated the entry into ARC and that community dwelling older adults who have history of falls generally tend to have lower level of physical activity, which may be due to fear of participating, leading to a loss of confidence to maintain normal life activities after an episode of fall.

Similar results have been reported by Jefferis et al (2014), in a study that investigated how falls and fears of falling are associated with physical activity among community dwelling older adults in the United Kingdom. A cross-sectional cohort of 1680 men aged 71–92 years recruited from primary care practices were monitored for their fall history in the previous 12 months. The authors reported that compared to men who did not fall, those with a history of fall were significantly older, had more mobility difficulties outdoors, left the house less often, had higher prevalence of depression, lower exercise self-efficacy and lower quality of life. Subsequently, considering these findings, one can infer that regular occurrence of falls among COPD older adults limits participation in activities which, in turn decreases strength and balance and initiates a downward cycle towards losing independence and entering ARC.

Although the relationship between ARC entry and falls for people with COPD is strong in this study, as described by the effect size, after adjusted alongside Activities of Daily living, this relationship and effect became less strong. This is consistent with the findings in a longitudinal study of falls predicting institutionalisation in older persons in the United States. It was

reported that the relationship between falls and subsequent placement in ARC was less strong after adjustment for the ability to perform activities of daily living due to frequency of falls and how frailty transition occurs (Dunn, Furner, & Miles, 1993). Community-dwelling COPD elderly, with poor ADL capabilities and a history of falls are more likely to enter ARC. Falls was found to result in a decline in function as a result both of physical injury and of a loss of confidence with regard to the ability to perform functional activities (Tinetti et al., 1994; Tinetti & Williams, 1997). Prior to this study, there was no research on the impact of falls on ARC entry specifically for a COPD cohort, despite many international studies on the impact of falls on ARC entry.

A major finding from this study showed that pain is a protective confounding variable. Protective variables are characteristics associated with a lower likelihood of negative outcomes or that reduce a risk factor's impact. Hence, this study found that pain was not associated with an increased risk of the likelihood of ARC entry, preventing the elderly with COPD from entry to ARC when changes occur in the functional capacity to perform ADL. Pain was captured using the interRAI Pain Scale. The Pain Scale was derived from assessments that attempt to define a person's level of pain. The Pain Hierarchy ranges from 0 (no pain) to 4 (daily excruciating pain). The result from the study showed that increase level of pain does not explain or translate into an elderly person with COPD moving into ARC. COPD community-dwelling older adults with poor ADL capabilities may enter ARC even though they are not experiencing pain. Although pain can be debilitating, it can often be managed well even in the face of complex needs.

A review and assessment of medication, and an understanding of pain intensity, frequency and the underlying cause of the pain may have resulted in the development of an effective pain management plan. Moreover, regular care and attention given to an elderly person might result in their pain subsiding. This is consistent with findings from Australia where it has been found that appropriate education and the development of pain identification and assessment scales for people with dementia, and proof-of-concept evidence for pain management approaches have been used to effectively managed pain among older adults (Savvas, Gibson, et al., 2015). Furthermore, the protective nature of pain against ARC entry for the elderly with COPD could be as a result of the rationalisation by older adults that pain is part of the ageing process, hence, they consider it 'normal'. A study in residential aged care facilities confirmed the notion that, compared with nurses, older adults more strongly endorse the belief that persistent pain is a

normal part of ageing and that there is little potential for improvement. Further findings from that study stated that other attitudes include fear of addiction to pain medications and reluctance to seek help for fear of an acknowledging disease progression or further functional dependence (Weiner & Rudy, 2002).

In another study conducted in Australia, the attitudes of stoicism and reluctance to accept medication are also age-dependent with older adults increasingly more cautious about labelling sensations as 'painful', and reticent in reporting pain. This was found to be the case among those who were over the age of 60 years (Yong, Gibson, de L. Horne, & Helme, 2001) and is consistent with findings that elderly people are generally less expressive of emotion and discomfort, leading researchers to conclude that self-reliance and stoicism may be abiding themes for many elderly people (Kunkel & Williams, 1991).

Evidence from previous research into the tendency of older adults to portray themselves in a positive light in relation to attitude scales appears to suggest that one reason for stoicism might be social desirability. A study found evidence of an age-associated response bias when using a self-report measure to examine age-related changes in mood states in older adults (Gibson, 1997). In contrast, in a more recent study that investigated trends of residents health status and functional profile prior to admission to ARC within different geographical areas in Iceland over an 11 year period (1996-2006) using the Minimum Data Set assessment, the frequency of pain reporting was high (Hjaltadóttir, Hallberg, Ekwall, & Nyberg, 2012).

The relationship between ARC entry and the effect of pain is protective for people with COPD in this study, although very mildly. This outcome is consistent with findings in a study assessing pain associated with activities of daily living in older adults in the United States in which it was found that pain in older adults is associated with only mild to moderate interference in ADLs (Koltyn et al., 2005). The mild to moderate nature of the effect size of pain in the presence of changing ADL might be attributed to the reluctance of the elderly to express pain, hence it might explain why pain in older persons is under-reported and not a significant reason for transition from the community into ARC. The inverse relationship between pain and ARC entry may be explained by variations in pain definitions and severity threshold, methods of reporting, and how other factors have been categorised across studies.

Ethnicity was found to be a protective factor in this study. Findings indicate that for this COPD cohort, substantial ethnic variations in ARC entry continue to exist irrespective of changes ADL capacity and that, among those who do not identify as Europeans, ARC entry risk is particularly low. This suggests that concepts of ageing and older people's preferences as they age may differ among ethnic groups. The majority of older people needing care, of any ethnic background, remain in the community and are cared for by family and friends. However, the extent to which family and friends provide assistance varies across ethnic group, reflects both cultural and socio-economic differences. Cultural explanations for the differences may be explained by consumers' attitudes, backgrounds, beliefs, and behaviours. The findings from this study indicate that older adults with COPD who identified as Māori or Pasifika have reduced risk of ARC entry irrespective of changes in ADL or decline in functional capacity.

A study demonstrating the concept of ageing positively in place among Māori argued that in a Māori worldview, land has a life-force and therefore it also has whakapapa (geneology), whānaungatanga (relationships), wairuatanga (spirituality), turangawaewae (place to stand) and ahi kaa (obligations to keep the home fires burning) (Williams, 2012). Māori have a physical, emotional, historical and spiritual relationship to land, and felt a great sense of attachment to the ancestral landscape. They felt a responsibility to maintain their traditional territories for others, such as children and grandchildren, to return to, hence they would rather stay in places they have connection to rather than move into ARC (Williams, 2012).

In another study considering the meaning of being aged and being Māori, it was argued that the concept of ageing and staying within the community is considered a deep spiritual act which cannot be exercised if they transitioned to an ARC facility. There is a purposefulness of meaning, bringing the past into the present and about being hopeful toward the future. There is a sense of contributing to something beyond the self; of giving for a common purpose in passing something on and in the readiness for leaving something behind (Wright St Clair, 2009).

Remaining in the community is a strongly held cultural belief among non-Europeans especially Māori, because of the end of life journey opportunity afforded kaumātua and whānau. The end of life journey provides an opportunity for kaumātua to grow closer to death, to move towards the ārai (veil). It is a process that requires support from whānau carers (extended whānau and formal carers). Everything that happens on the journey towards the ārai either contributes or diminishes the spiritual experience and well-being of kaumātua. Whānau who intentionally

provide care as an expression of whānaungatanga (connectedness), (love, care, concern), āwhi (affection, support) and manaakitanga (reciprocal care) help to strengthen their wairua for the journey home (Moeke-Maxwell, Nikora, & Te Awekotuku, 2014).

Pacific peoples generally prefer to care for older people or disabled family members within the family even when these elderly decline or cannot perform activities of daily living. One reason for this is that Pacific peoples are often uncomfortable sharing problems outside the family (Bacal & Jansen, 2010). Additionally, within many Pacific traditions, the central purpose of elders' lives includes their ability to act as guardians and pass on their heritage to their descendants hence the need live in close proximity to their children and grandchildren (Tamasese et al., 2014). This appears to be a consistent theme within other ethnic groups. For example, an early study in the United Kingdom, that aimed to identify best practice guidance in relation to caring for minority ethnic older people found the low uptake of people from the Indian sub-continent to ARC entry was linked to their perceptions of culturally inappropriate care, which included failure to cater to dietary needs, insensitivity to religious beliefs and practices, lack of interpreter of services and the absence of minority ethnic staff in ARC (Mold, Fitzpatrick, & Roberts, 2005). Similarly, in the United States, in a study conducted to explore how and why ARC entry differs by ethnicity, it was found that Hispanic and black adults are less likely to use nursing homes or go into ARC than white adults, and that this difference is magnified when taking into account the poorer health and fewer socio-economic resources of the black and Hispanic adults (Thomeer, Mudrazija, & Angel, 2015).

In contrast, the lower proportion of other ethnic groups when it comes to ARC entry could also be attributed to the health characteristics of these groups. They are somewhat considered to have low socio-economic and poor health status, such as shorter life expectancy, as found in previous studies. Edwards (2010) reported in his study on Māori positive ageing that Māori have a shorter life expectancy than non-Māori, with most passing away between the ages of 65 and 79 years compared to most non-Māori who pass away in the over-80-year age group. Moreover, older Māori are also more likely than non-Māori to be of lower socioeconomic status (Wham, Maxted, Teh, & Kerse, 2015).

Loneliness is a major contributor in explaining why elderly move into ARC when there is a decline in ADL capabilities. It can be argued based on this study's outcome that, due to declining health status and functionality (captured with ADL), elderly people in the COPD

cohort have reduced social networks. This in turn results in the loss of intimate and social relationships and hence the need to move to a place where to some extent loss of relationships can be mitigated. Historically, loneliness has been conceptualised as an unpleasant situation crated by lack of quality relationships. These include situations in which the number of existing relationships is smaller than is considered desirable, as well as situations where the intimacy one wishes for has not been realised (de Jong-Gierveld, 1987), or the unpleasant experience that occurs when a person's network of social relations is deficient in some important way, either quantitatively or qualitatively (Perlman & Peplau, 1981).

Loneliness is increasingly part of the experience of growing old. Several studies have reported rates of severe loneliness among older adults. A study conducted in North Wales reported rates of severe loneliness among older adults aged 65 and over were found to be between 2% and 16% (Wenger, Davies, Shahtahmasebi, & Scott, 1996), while in the Netherlands and Italy at any one point in time was found to be up to 32% of individuals aged over 55 (Gierveld & Van Tilburg,1999). Loneliness was reportedly a high concern of older people in an epidemiological study of long-term care facility admissions to various types of institutions in Belgium (Devroey, Casteren, & Lepeleire, 2002). A study that examined loneliness in association with health status, residential care, partner status, and network size over a seven-year period among adults born between 1908 and 1937 in Amsterdam (Dykstra, Van Tilburg, & Gierveld, 2005) reported older adults become lonelier as time passed.

Recent descriptions of loneliness in the literature have included a perception of social deprivation, distinct from the objective social isolation that has been associated with accelerated functional decline and increased mortality in older adults. A longitudinal cohort study of 1604 participants in the psychosocial module of the Health and Retirement Study, a nationally representative study of older persons in the United States, investigated the relationship between loneliness, functional decline and mortality. The authors reported that loneliness was associated with all outcome measures and subjects were more likely to enter ARC when they experience decline in ADL (Perissinotto et al., 2012).

More than half of the elderly in this study of people with COPD have lost a partner, resulting in a reduction in the number of existing relationships. This reduction may result in loneliness and lack of ability to cope (loss of ADL capacity) thereby resulting in an elevated risk of ARC entry. This potential outcome was found in a multi-wave prospective study looking at the

effects of spousal bereavement over time in the United States, in which loneliness was found to be especially strong among the bereaved elderly. It was this feeling of loneliness that activated other non-coping ability symptoms such as depression, risk of suicide, engagement in risky health behaviour, including smoking, drug or alcohol abuse, failing to care for themselves, or generally becoming more inactive, and at increased risk of dementia. The research further suggested that those widowed who had been highly dependent on their spouses were more likely to develop problems with anxiety, and that the loss of previous very close relationships can also lead to greater loneliness for surviving spouses (Wortman et al., 2000).

Pre-existing or chronic conditions of ill health and decline in mobility may also leave the elderly less able to socialise and, in turn, likely to experience loneliness. This challenging situation, i.e. processing and dealing with the medications, symptoms and life changes, might also affect the social life of an elderly person such that they may withdraw from activities once cherished, making it hard to nurture friendships and close relationships. Elderly people with chronic illnesses often have to make choices for themselves that leave them more socially isolated, which is a risk factor for poor coping, depression, feelings of loneliness and anxiety. This argument is consistent with the findings of a study examining the relationship between loneliness and health and well-being in older adults. The research found that many older adults are at risk of loneliness because of declining health and other age-related losses that prevent them from remaining engaged in meaningful relationships (Smith, 2012). Based on these findings, it can be assumed that loneliness could be alleviated with more meaningful social interaction within the community.

5.5 JIDE Composite Score

This study has resulted in the development of a six-item 4-level composite score that categorised interRAI-HC assessed community-dwelling older adults aged 65 and older who have COPD into risk groups of transitioning into ARC. The items included in these four-level composite score are well known predictors of ARC entry among older people. They are Activity of Daily Living (ADL) captured by the ADL Hierarchy Scale, ethnicity, history of falls, cognition (captured by Cognition Performance Scale (CPS)), loneliness, and pain (represented by the Pain Scale). These factors have been fully described in the literature and the discussion sections of this study.

The composite score is a simple scoring system to stratify elderly persons with COPD into minimal, marginal, moderate and high risk category for functional decline and subsequently ARC entry after undergoing interRAI-HC comprehensive assessment. This is consistent with previous studies of using functional decline as an indirect measure of ARC entry. Using a predictive index for functional decline in hospitalised elderly patients in the United States, a simple predictive model based on four risks (cognitive impairment, functional impairment, low social activity level and decubitus ulcer) was found to have been reliable in identifying elderly patients at greatest risk (Inouye et al., 1993). In a similar study in the United States that comprehensively examined factors associated with ARC entry from 6 domains of older adult and family caregiver risk, based on the prognostic stratification into risk quintiles, the authors reported that ARC entry risk was 7.0% in the lowest quintile, 20.4% in the middle 3 quintiles, and 30.9% in the highest quintile (Wolff et al., 2018).

The JIDE composite score for elderly persons with COPD has a moderate predictive discriminatory ability both in the training and testing groups. This can be explained by the fact that only participants who have had a baseline assessment were used, based only on identified variables without the use of additional biological, clinical or social variables. The predictive discriminatory ability of the composite score is similar to those of other studies. Sager et al (1996) found a ROC area of 0.65 during the development of the HARP referred to in Chapter 2 used in identifying older patients at risk for functional decline following acute medical illness and hospitalisation (Sager et al., 1996). Similarly, in recent study in the United States that comprehensively examined factors associated with long-term nursing home entry from 6 domains of older adult and family caregiver prognostic risk model, the model was well calibrated and demonstrated moderate discrimination (c-statistic=0.670 in the original data, c-statistic=0.647 in bootstrapped samples, c-statistic=0.652 using the point-scoring system) (Wolff et al., 2018). Furthermore, in a study predicting the functional status outcome of elderly aged 80 years and older also in the United States, a value of 0.81 for the predictive model of functional decline was found but when interview variables only were used, the ROC value was 0.77 (Wu et al., 2000).

Additionally, in a study detecting older people at increased risk of adverse health outcomes based on the ISAR screening tool referred to in Chapter 2, the discriminatory ability of the tool was found to be 0.70 (McCusker et al., 1999). An Italian study evaluated the predictive validity of ISAR for elderly patients presenting to the emergency department. The authors reported the

identification of Italian elderly ED patients who have an increased 6-month risk of death, ARC placement, functional decline, ED revisit, or hospitalisation. Sensitivity and specificity were 0.85 and 0.41 respectively (Salvi et al., 2009). In predicting the risk for poor outcomes in older patients discharged from an emergency department in the Netherlands, ISAR had a moderate performance of 0.60 (Buurman et al., 2011). The Identification of Seniors at Risk (ISAR) score to predict clinical outcomes and health service costs in older people discharged from UK acute medical units had an AUC performance of 0.60 (Edmans et al., 2013).

The composite score derived for the COPD cohort in this study performs in a similar way and as well as other scores. It can be argued that it can be used in several settings and populations and also help in predicting other outcomes of similar interests. The composite score developed for community dwelling older adults with COPD has four-level risk category- low, mild, moderate and high. Individuals with COPD in high level category of the composite score are three times at risk of ARC entry compared to those in low level category, while those in the moderate level category are at twice the risk of ARC entry compared to those in the low category. Given the increase in the older population in New Zealand and the increase in associated functional decline and frailty due to chronic condition such as COPD, identifying those in the community likely to develop adverse outcomes is important, to allocate existing resources more effectively. Risk assessment and the use of risk prediction models has produced valid quantitative ways of expressing risk that can balance the potential costs and benefits (Kansagara et al.,2011).

Based on the incremental explanation this score offers, it can assist in early identification of those elderly who have COPD and are at risk of decline and ARC, and set the stage for the provision of appropriate interventions. The category of risk based on this composite score can be used as basis for clinical planning. Using the JIDE composite score, an elderly person with COPD who has been categorised as high risk is expected to immediately undergo a plan of action for possible transition to ARC while those categorised to have minimal risk are expected to be placed on plans to manage the decline and provide support services to keep them at home as long as possible. The ability to stratify risk can help physicians to explain risks to older adults and families and can help families to better understand the interventions and potential outcomes (Inouye, Westendorp, & Saczynski, 2014). It will also allow a better basis for service design and planning.

5.6 Impact of factors contributing to ARC entry time for people with COPD

5.6.1 Functional decline and associated variables impact.

Consistent with the previous studies, this study found that in all persons of 65 years of age and above who have been diagnosed with COPD, the hazard or instantaneous risk of entry into residential care was associated with ADL (change in functional capacity) as an independent hazard after adjustment for ethnicity, history of fall, cognition, loneliness and pain frequency. The analyses of this study support the hypothesis that, for older persons, the change in functional capacity to perform ADL increases the hazard of entry to ARC, after controlling for ethnicity, history of fall, cognition, loneliness, pain frequency and age. The impact of these variables in determining how long it takes to enter ARC in the study were very high.

The findings of change in the potency of variables have potential implications for understanding past research findings. This study found that those in the COPD cohort with higher ADL scores levels were 1.3 times more likely to enter ARC than those with lower levels of ADL scores over time, and this is particularly instructive in the context of Miller and Weissert's (2000) synthesis of research, which revealed across twelve research studies that higher ADL impairments levels were associated with increased hazard of institutionalisation. Similarly, those in the COPD cohort with higher levels of cognitive impairment were 1.24 times more likely to enter ARC over time than those with lower levels of cognitive impairment and, in the context of the same Miller and Weissert synthesis (Miller & Weissert, 2000), it was reported that lower cognitive functioning was associated with increased hazard of institutionalisation in 25 of 33 studies.

In a systematic review of the predictors of institutionalisation in the elderly, variables with strong evidence were increased age, low self-rated health status, functional and cognitive impairment, dementia, and a high number of prescriptions (Luppa et al.,2009). Furthermore, the authors suggested that predictors of ARC entry are mainly based on underlying cognitive and/or functional impairment, and associated lack of support and assistance in daily living which are consistent with the findings of this COPD cohort study.

In a recent study to estimate the incidence of ARC entry and to identify predictors of placement among older people in Alberta, Canada during a 12 month follow up, the cumulative incidence of ARC admission was 18.3 per cent by 12 months and a significantly increased hazard for

ARC entry was observed for older residents (i.e., age 85+) and those with poor social relationships, little involvement in activities, mild and more severe cognitive impairment, limited and more extensive ADL impairments, moderate to high health instability and recent falls (Maxwell et al., 2013). In the COPD cohort in this thesis, an increased hazard of ARC entry was observed for elderly adults based on their cognition score (HR=1.24 95% CI=1.20-1.29) when there is a change in functional capacity, a finding consistent with other research involving community-dwelling older adults. A similar study, though not recent, that investigated the determinants of moving to ARC during a 3-year follow-up in Sweden found that Lower MMSE scores were associated with living in an institution and cognitive performance predicted future institutionalisation (Agüero-Torres, Von Strauss, Viita- nen, Winblad, & Fratiglioni, 2001).

In the same vein, members of the COPD cohort in the current study, who reported at least one fall in the last 90 days were 1.30 times more likely to enter ARC than those who have never reported a fall over time when there is a change in functional capacity. The low ARC-admission free level as a result of history of fall is unexpected. In the early 1990s, a study that determined the frequency of and hazard from fall among 409 non-institutionalised community-dwelling persons aged 65 years or more in west-central Montreal, Quebec, Canada, reported that 30% over 65 and 50% of those over 80 fall each year and that these people who fall once are two to three times as likely to fall again within a year (O'Loughlin, Robitaille, Boivin, & Suissa, 1993). Recent findings from a study in China that investigated the rate of falls among community dwelling adults aged 60 years and over using a multistage random sampling indicated that more falls occurred in older Chinese people with a current of a medical condition (H. Zhou, Peng, Tiedemann, Peng, & Sherrington, 2019).

Expressing loneliness predisposes members of the COPD community-dwelling adult over time to ARC entry 1.31 time more than those who have not expressed being lonely in this study. While loneliness was found to have an increased hazard of ARC entry, some recent studies have also reported that engagement in activities and social relationships may postpone functional and/or cognitive decline leading to higher levels of being ARC admission free. One recent study in the United States that tested the hypothesis that a higher level of social activity was associated with decreased hazard of decline and ARC entry among community-dwelling older adults reported that the hazard of decline in activities of daily living decreased by 43% (HR = 0.57, 95% CI = 0.46-0.71) (James, Boyle, Buchman, & Bennett, 2011).

Ethnic identification impacts time it takes to enter ARC when changes occur in ADL. The outcome from the COPD cohort in this thesis showed that being a Pasifika increased being ARC admission free by 74% more compared to being European. Similarly, being ARC admission free among Māori is 45% higher. This suggests that ethnic differences in time it takes for ARC admissions persist for the elderly with COPD, perhaps due to cultural aversion or structural obstacles. Cultural aversion might mean greater preference for family care and discouraging institutionalisation. This is consistent with findings already discussed that the likelihood of ARC entry or remaining in the community has a strong cultural basis among non-Europeans (Moeke-Maxwell et al., 2014).

Pain has been shown in this study to decrease the hazard of ARC entry among COPD community dwelling adults who have undergone interRAI assessment. The hazard of pain in this study is protective. High pain frequency is 0.92 times less likely to increase the time of ARC entry. This is consistent with findings in the literature. A study in residential aged care facilities also confirmed that, compared with nurses, older adults more strongly endorse the belief that persistent pain is a normal part of ageing and there is little potential for improvement (Weiner & Rudy, 2002). As expected, increase the unit of age increased the hazard of ARC entry.

Assessing the impact of functional decline and associated covariates on how long it takes to be admitted to ARC or otherwise has several implications. In particular, this would allow adequate assessment of an older person's risk of entry into ARC as well as to develop strategies to prolong community dwelling.

5.6.2 Impact of functional decline on mortality and ARC entry.

When death is accounted for as a competing risk, COPD community dwelling older adults in this study are more likely to die than enter ARC. The COPD cohort have twice as much risk of dying as entering ARC between 6-12 months of undergoing interRAI assessment. Additionally, COPD community-dwelling older adults who are dependent in their ADL are more likely to die than enter ARC. The ADL dependent COPD cohort are three times likely to die within 6 months of undergoing interRAI assessment.

These outcomes raises important issues. It is possible that for these COPD community-dwelling older adults, assessments were not done early enough and/or at the appropriate time. There may

be some other underlying conditions. The unknown severity of COPD for community-dwelling older adults in this study may have significantly impacted the incidence of death when there is a change in ADL or functional decline occurs. The design of the interRAI assessment instrument might not have captured certain vital medical, physiological, social and psychological details of the older person. It is possible to envisage that at all times, when information is being captured, assessors may not have maintained an understanding of the older person's perspective. In a study that examined the completion of interRAI Home Care assessments, the possible causes for incomplete assessments and the consequences of these factors with respect to the quality of care received in Belgium, the authors reported that a lack of information may result in increased assessment burden, uncoordinated care and adverse events influencing morbidity, mortality, hospitalisation and institutionalisation (Vanneste, Mello, Macq, Van Audenhove, & Declercq, 2015).

Evidence of the diagnosis of COPD, treatment and monitoring were captured with the interRAI assessment instrument in this study. However, the severity of COPD was not. The severity of COPD was discussed in Chapter 1 based on the GOLD approach. The GOLD approach using the ABCD assessment protocol reflects adequately the complexity of COPD severity staging and forms the basis of the guide to COPD management. We do not know whether COPD severity for community-dwelling older adults in this study is mild, moderate, severe or very severe. The severity of COPD may have been a reason why COPD elderly in this study die rather than enter ARC when they experience functional decline. Vanneste et al (2015) argued that the assessment of the functional status of the client seemed to be more demanding and that understanding ADL and IADL requires thorough observation, thinking and information gathering with regard to the frail older person's presumed ability to carry out an activity (Morris et al., 2006). A better indication of disease severity may assist with this.

5.7 Summary

COPD and rapidly changing needs of community-dwelling older persons increase the complexity of caregiving. COPD greatly impacts the health of an elderly person, leading to a reduction in the quality of life or requirement for prolonged assistance including risk of becoming functionally declined or dependent on others. A comprehensive, systematic and structured collection of data on the status of these elderly persons is essential in facilitating decision-making and thus improving the quality of care provided. interRAI is designed to

identify individuals with the greatest needs for support and service delivery, and will capture this in an older population.

There is ample evidence from the literature that there is a general research on COPD and its risks of causing functional decline, the burden of ARC and the risk of entry for community dwelling older adults. Unfortunately, there are no international studies that draw these themes together. The results of this thesis indicates that in all community-dwelling persons of 65+ years of age who have been diagnosed with COPD, the risk of entry into residential care was associated with poor ADL capacity and associated covariates such as ethnicity, history of fall, cognition, loneliness and pain frequency. Lower capacity to carry out ADL, regular occurrence of falls, cognitive impairment and loneliness increases the risk of ARC entry. Being non-European and pain levels decreases the risk of ARC entry. The impact of death and ARC entry differs when functional decline occurs. COPD community-dwelling older adults in this study are more likely to die than enter ARC. Information about whether the severity of COPD is mild, moderate, severe or very severe is unknown. This may suggest why COPD elderly in this study die rather than enter ARC.

Given the increase in the older population in New Zealand and the increase in associated functional decline, frailty and death due to chronic condition such as COPD, assessing the impact of functional decline is important in identifying those in the community most likely to develop adverse outcome. The JIDE composite score can assist in early identification of those are risk of decline and ARC and set the stage for the provision of appropriate interventions.

CHAPTER SIX

Conclusion

The previous chapter explored other research that builds on to and adds meaning to the analysis within this study. This chapter summarises the main areas of interest in relation to the research objectives.

6.1 Reflecting on the objectives of the study.

This thesis aimed to assess the independent impact of functional decline on transition to aged residential care (ARC) for community-dwelling older adults with COPD after adjustment for all other potential confounding variables, and on that basis develop a risk stratification score. The objectives of the study appeared primarily technical, but the analyses proved both challenging and revealing. It is challenging in that this is the first research assessing the relationship between COPD, functional decline and ARC entry risk. Secondly, in exploring this relationship, the hypothesis that COPD diagnosed community-dwelling older adults with better ADL capabilities are less likely to enter ARC in the presence of other factors was tested. The result revealed that community-dwelling older adults with confirmed COPD diagnosis and lower ADL capabilities are more likely to enter ARC when they experience higher levels of cognitive impairment, loneliness and a history of falls. Additionally, culturally specific differences are evident in the ways in which COPD diagnosed community-dwelling older adults experience and adapt to community-based living or ARC when changes occur in their functional capacity. The risk stratification resulted in the development of the JIDE score. The score characterises the journey from an independent to a dependent-living environment. The score assesses functional decline in community-dwelling older adults with COPD and subsequently categorises them into potential risk groups. Those in the high category are at an increased risk of entering ARC. The result also revealed that mortality is still a major issue among community-dwelling older adults whether the goal is the management of elderly people in the community or residential care.

In achieving these objectives and for the first time, research that has addressed the role of functional decline as risk factor for ARC admission among community dwelling elderly with COPD is produced.

Additionally, a major impact of this study is on those who remained in the community despite experiencing changes in capacity to perform ADLs- the Māori and the Pasifika groups. Based on the 2013 New Zealand census data, 3.3% of 65 years and over in residential care were Māori and 1.5% were Pacific peoples compared to 93% who identified as Europeans. This research impact is enormous because according to Statistics New Zealand, by 2026, the population of Māori and Pasifika who will be 65 years and above will increase by 115% and 110% respectively as discussed in the introduction chapter. This research has shown that appropriate and directed culturally sensitive well-being policy to live well-respected and independent lives is needed to address this growth.

Secondly, the cultural/ethnic implications of this research is a positive attempt to further improve the collective approach to the Māori Health Strategy of healthy future, healthy individual, health family and healthy environment. Māori /Pasifika older adults should be confident of a future, be surrounded by people they love and want to be with in an environment they cherish receiving appropriate well-being support.

Finally, for the Māori and Pasifika older adult population, the JIDE Score is an important tool to collaboratively address health inequalities, deliver higher quality and effective services that supports their health and well-being in a timely manner.

6.2 Strengths and Limitations of the Study

This study utilised data from interRAI and assessed whether community-dwelling older adults with COPD and better ADL capabilities will remain in the community or move into ARC in the presence of potential confounders.

The sampling and the sample size are strengths of this study. The sample of the study comprised a large cohort of community-dwelling older adults who have been diagnosed with COPD. This cohort was a pool from the general population of the elderly and therefore the outcome of the study can be generalised. The large sample size of community-dwelling older adults as sample for the study potentially prevents model bias of the JIDE score. The sample was large enough to accommodate both training and testing groups. This was advantageous because it helped to assess how well the models in the study behaved when applied to new data i.e. assessment of how the results of the statistical analysis generalise to an independent data set.

In terms of the research instrument, the interRAI-HC, data quality was very good. Completion rates were very high, with fairly no missing values, a likely consequence of having largely compulsory questions as it is in most cases part of routine care that is mandatory for every elderly person in New Zealand wishing to access services. Those assessed provide explicit informed consent for use of their de-identified information for planning and research purposes. The validity of the data is also high as it is a psychometrically validated instrument that predominantly uses variables with defined response categories. The interRAI-HC provides an invaluable growing repository of information for health research to improve outcomes in New Zealand.

Exploratory multivariable regression analyses was used to model and stratify risk. This is an analytical tool that produces empirically sound explanatory representation of the contributing factors for ARC entry as important confounding factors were accounted for.

Nonetheless, a number of limitations of the study have been identified. The use of a proxy, where assessors completed the interRAI-HC based on their knowledge about the older adults' health condition, and not older adults themselves, is a potential limitation. Although, the reliability and validity of proxy data is found to be high for tasks of daily living and health conditions that are easily observed, it has been reported to be relatively low for conditions that are more sensitive and less likely to be reported (Lynn Snow, Cook, Lin, Morgan, & Magaziner, 2005).

The data presented was that of the COPD cohort within the interRAI dataset. Given that the interRAI and NZ census differ (see table 4.1), it is acknowledged that this might be an issue and a limitation of the study as not everyone with COPD will have an interRAI assessment within the time frame for the research.

The study was limited to the variables available in the interRAI 9.1 New Zealand customised version and may not have captured all relevant and known risk factors for ARC entry particularly for COPD. The capture of additional variables has the potential to reflect the complexity of COPD. If a better understanding of the severity and impact of COPD on community-dwelling older adults who have been assessed could have been gained, this would have given a more robust overview of the status when other co-morbidities are considered.

6.3 Contributions of the Research

Chapter 2 and 5 of this thesis outlined and discussed the research into COPD and functional decline, and the risk of ARC entry for community-dwelling older adults. This study, to the best of the researcher's knowledge, is the first population level study that addresses COPD, functional capacity and ARC entry risk using the best available data captured with a standardised and validated instrument. The interRAI instrument is consistently high in terms of reliability, validity, completeness and have a low rate of logical errors.

Addressing issues of functional decline, ARC entry specifically for those with COPD is an important research contribution. COPD remains a serious and complex chronic condition that imposes substantial personal and financial burdens on the affected individuals, their families, and society at large. There is a need for more population studies to understand and enable the provision of services or interventions to redress this situation—particularly with the ageing population projections available for increases in New Zealand and elsewhere. This research represents a study responding to this specific problem. These results have the potential to directly impact on the management of the increasing population of elderly people with COPD, and provide an empirical basis for the body of literature for the understanding the nature and extent of the risks and hazards, as it currently exists, upon which informed planning can be based.

In pulling together data on COPD, functional decline and ARC entry, this study has shown that community-dwelling older adults with confirmed COPD diagnosis and lower ADL capabilities are more likely to enter ARC, when they experience higher levels of cognitive impairment, loneliness and a history of falls. These are specific indicators, some of which can be mitigated by undertaking early medical evaluation and review, optimising environmental stimulators, assessment and modification in surrounding environment to encourage confident independence and mobility, or community-based strategies for those who are expected to remain in the community or transitional care plans for those who may move into ARC. Additionally, this study has further highlighted, and added to the body of knowledge about the influence of cultural practices and entry of older adults to ARC. Cultural beliefs are significant to the older person's experience of well-being and subsequent provision of health care services. This study has thrown light on the need to recognise and respond to potential culturally specific differences in ways in which community-dwelling older adults experience and adapt to community-based living or ARC when changes occur in their functional capacity.

A new composite score based on interRAI instrument data has been developed. This composite score-Journey from Independent to Dependent-living Environment (JIDE) composite score - categorised community-dwelling older adults who have COPD into four risk levels entering residential care. These risk levels are low, mild, medium and high. High category group on the JIDE score are comprised of those who have the highest risk of entering residential care compared to the low category. This composite score is a significant and novel contribution to the field of prognostic outcomes that can assess functional decline in community-dwelling older adults with COPD and subsequently, the likelihood of entry into aged residential care from the community. Accurately identifying community-dwelling COPD elderly at increased risk of entering ARC when there is a significant change in functional capacity (ADL) would provide substantial public health benefits.

Firstly, as discussed extensively in this thesis, 42% of the health services in New Zealand are utilised by the older people and with increase in the demography of the ageing population, healthcare spending has doubled than the overall expenditure of the older population and 60% of this expenditure is utilised exclusively in ARC services. Population ageing without health improvement in chronic conditions such as COPD will cause this share to increase. The ability of the JIDE score to categorise into low, mild, medium and high risk profiles potentially identifies more precisely the health needs of each categorised groups. Financial implications are known, and targeted spending to meet such precise health needs can then be executed. This may have major impact on healthcare spending whether the elderly remained in the community or moved into ARC.

Secondly, when it is known, through the JIDE score that a group of elderly are at an increased high risk, resource allocation can be prioritised, and the utilisation of such resource can be directed to those who require them most. This mean that older people found to have high or complex health and disability support needs will potentially have access to flexible, timely and co-ordinated services and living options that may proactively improve and maintain their health and functioning capacity. They will also have a timely and effective assessment clinically effective and tailored to their needs.

The JIDE composite score has been developed using a large number of community dwelling older adults who have been diagnosed with COPD and these results may be generalised to cohort of individuals with specific diagnoses within the interRAI population in New Zealand

and possibly around the world. Furthermore, the composite score derived in this study, the Journey from Independent to Dependent-Living Environment (JIDE) score, has a logical flow and is easily interpretable. It is believed the use of the within the home care and ARC settings will enhance decision making for individuals. Additionally, having informed knowledge about the level of risk elderly with COPD diagnosis are exposed to through the JIDE score, there is the potential of improved participation and co-operation from them to ensure COPD management goals are followed and achieved for improved functional capacity health outcomes whether in the community or ARC. Older people and their families are also able to make well-informed choices about options for healthy living, healthcare and/or disability support needs.

The findings of this study provide support for the discriminatory and predictive properties of the interRAI HC instrument. By developing the JIDE score using the interRAI data, the composite score may have implications for health strategy, service delivery and care planning that may impact policy choices for vulnerable community-dwelling older adults. The score stratifies older adults with COPD into risk groups that can potentially be used as an aid to support clinical and geriatric decisions in the care planning process and may be incorporated as part of a comprehensive clinical assessment where the preference of the older adult is considered. Furthermore, the development of a holistic, person-centred approach that promotes wellness, as well as collaboration among key sectors leading to a reduction in barriers to positive ageing for the benefit of older people who suffer from COPD is potentially ensured.

6.4 Future developments

Although this study has contributed new information on the likelihood of aged residential care entry and prognostic outcomes for the COPD population within the interRAI data, gaps still exist, and suggestions are made here for future research.

COPD is a debilitating chronic condition and often under-diagnosed. This may potentially lead to serious complications. For elderly people with declining functional capacity as they age, it is more pronounced. Future research should focus on early identification of people at risk of developing COPD. For community-dwelling elderly people, investigation of early life and childhood factors are potential factors that should be researched. When this occurs, risk prediction models that incorporate the best available evidence in order to stratify older adults

based on their individual risk profiles that could potentially facilitate early detection, accurate diagnosis, determination of prognosis, early targeted interventions and management of COPD is another research area that could be given attention. This understanding of the dynamic nature of COPD has the potential to offer new windows of opportunity for prevention and treatment.

Future research could focus on comparing the JIDE composite score to other prognostic stratification outcomes, developing a Clinical Assessment Protocol (CAP) for the score and evaluating the performance of the JIDE score in other settings. This might mean that external validity of the study is required. This is essential to ensure that it is fit for purpose and a continuous improvement in outcomes. Also, the potential of this prognostic score should be evaluated, through modelling and impact studies, and ascertain if further enhancement in its performance can be obtained.

Other diseases and condition diagnoses exist within the interRAI data. They include neurological diseases such as Alzheimer and stroke; musculo-skeletal diseases such as fractures; other cardiac or pulmonary diseases such as congestive heart failure and coronary heart failure; psychiatric diseases such as anxiety and depression; infections as well as health conditions like fatigue and sleep disorders. Many of these disease and health conditions are common among elderly people. They have significant implications for their well-being as well as living options, whether in the community or ARC, when changes in functional capacity occur. A standard methodology for developing the models that assesses functional decline and its impact on ARC entry for community dwelling older adults for these diseases and conditions can be investigated. The JIDE score has provided some methodological approaches that can be built on. This may potentially lead to the development of an integrated approach in the management of functional decline across all spectrum for community dwelling older adults. When standard methodologies in models that assess functional decline and its impacts on ARC entry for community-dwelling older population are researched, it is recommend that further research in testing these prognostic models in a wide range of clinical settings, including outpatient services, emergency departments, medical ward, intensive care units and primary care structures could be undertaken. Future prognostic research should steer towards recalibration or update of existing prognostic models with the addition of new predictors to enhance their prognostic performance.

There is potential to use this study outcome for policy and planning. It might be that, if we expect a certain proportion of people with COPD to go into ARC or stay in the community and these expectations are not been met due to death or other reasons, what is unknown is how this compares with other medical conditions or why the rate of death is high, and whether there would be an opportunity to try and lower that level of that rate of entry to ARC or death. With a database such as interRAI, and the opportunity to calculate levels of entry, we might then begin to think of intervention strategies that could be researched based on risk stratification for different conditions.

6.5 Final thought

In conclusion, it is clear that ageing will continue to be a growing issue worldwide and in New Zealand. Changes in functional capacity will continue to occur as a result of ageing. Chronic conditions such as COPD do not fix themselves. Some are life threatening while others linger over time and need intensive management. How the society provides support for an increasingly large and vulnerable population will continue to be a political, economic, health and social challenge. New Zealand has responded to this challenge by developing systematic policy for both assessment and access to care. Significant resources have been committed. Given this, it is essential that researchers play their part in contributing to this through robust analysis and thoughtful interpretation. This thesis, it is hoped, is in the spirit and tradition of such contributions.

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Appendices

Appendix A: interRAI Home Care Assessment

interRAI™ HOME CARE (HC) ASSESSMENT FORM
Version 9.1 © InterRAI 1994–2009
New Zealand Customisation

SECTION A: IDENTIFICATION INFORMATION

1. NAME
a. (First) b. (Middle Initial) c. (Last)

2. GENDER M. Male F. Female U. Unknown I. Indeterminate ☐

3. BIRTHDATE

4. MARITAL STATUS ☐
1. Never Married
2. Married/Civil Union/Defacto
3. Widowed
4. Separated
5. Divorced
6. Other

5. NATIONAL HEALTH IDENTIFIER
a. **NHI NUMBER**
b. **Does the person have a current community services card for this assessment?** 0. No 1. Yes ☐
c. **ACC CLAIM NUMBER:**

6. FACILITY / AGENCY NUMBER

7. ELIGIBILITY FOR PUBLICLY FUNDED HEALTH SERVICES IN NEW ZEALAND *[check all that apply]*
a. New Zealand resident/citizen ☐
b. Work Visa ☐
c. Australian resident in NZ ☐
d. UK or Australian visiting NZ ☐
e. ACC accepted claims ☐

8. REASON FOR ASSESSMENT ☐
1. First Assessment
2. Routine Assessment
3. Return Assessment
4. Significant change in status reassessment
5. Discharge assessment covers last 3 days of service
6. Discharge tracking only
7. Other – e.g. research

9. ASSESSMENT REFERENCE DATE

Are you happy for your assessment information to be used for planning and research? Your name, address and any other identifying information will be removed.
0. Client or person entitled to consent on behalf of client agrees.
1. Client disagrees or is not competent to make informed choice or person entitled to consent on behalf of client disagrees. ☐

10. PERSON'S EXPRESSED GOALS OF CARE

Primary Goal

11. DOMICILE CODE OF RESIDENCE
Domicile code of usual living arrangement

12. RESIDENTIAL / LIVING STATUS AT TIME OF ASSESSMENT ☐
1. Private home/apartment/rented room
2. Board and care
3. Assisted living or semi-independent living
4. Mental health residence—e.g., psychiatric group home
5. Group home for persons with physical disability
6. Setting for persons with intellectual disability
7. Psychiatric hospital or unit
8. Homeless (with or without shelter)
9. Long-term care facility (nursing home)
10. Rehabilitation hospital/unit
11. Hospice facility/palliative care unit
12. Acute care hospital
13. Correctional facility
14. Other

13. LIVING ARRANGEMENT ☐
a. **Lives**
1. Alone
2. With spouse / partner only
3. With spouse / partner and other(s)
4. With child (not spouse / partner)
5. With parent(s) or guardian(s)
6. With siblings(s)
7. With other relatives
8. With non-relative(s)

b. **As compared to 90 DAYS AGO (or since last assessment), person now lives with someone new e.g., moved in with another person, other moved in** 0. No 1. Yes ☐

c. **Person or relative feels that the person would be better off living elsewhere** 0. No 1. Yes ☐

14. TIME SINCE LAST HOSPITAL STAY ☐

Code for most recent instance in LAST 90 DAYS

0. No hospitalisation within 90 days
1. 31–90 days ago
2. 15–30 days ago
3. 8–14 days ago
4. In the last 7 days
5. Now in hospital

SECTION B: INTAKE AND INITIAL HISTORY

[Note: Complete at Admission/First Assessment Only]

1. DATE CASE OPENED

2. ETHNICITY *[check at least one but no more than three options]*

10 European not further defined	41 Southeast Asian
11 New Zealand European	42 Chinese
12 Other European	43 Indian
21 Māori	44 Other Asian
30 Pacific peoples not further defined	51 Middle Eastern
31 Samoan	52 Latin American / Hispanic
32 Cook Island Māori	53 African (or any group of African origin)
33 Tongan	61 Other ethnicity
34 Niuean	94 Don't know
35 Tokelauan	95 Refused to answer
36 Fijian	97 Response unidentifiable
37 Other Pacific peoples	99 Not stated
40 Asian not further defined	

3. PRIMARY LANGUAGE *[see manual for codes]*

4. RESIDENTIAL HISTORY OVER LAST 5 YEARS

Code for all settings person lived in during 5 YEARS prior to date stay began (Item B1) 0. No 1. Yes

a. Long-term care facility—e.g., nursing home ☐
b. Board and care home or assisted living ☐
c. Mental health residence—e.g., psychiatric group home ☐
d. Psychiatric hospital or unit ☐
e. Setting for persons with intellectual disability ☐

SECTION C: COGNITION

1. COGNITIVE SKILLS FOR DAILY DECISION MAKING

Making decisions regarding tasks of daily life—(e.g., when to get up or have meals, which clothes to wear, or activities to do.

0. **INDEPENDENT**—decisions consistent/reasonable/safe ☐
1. **MODIFIED INDEPENDENCE**—some difficulty in new situations only
2. **MINIMALLY IMPAIRED**—in specific situations, decisions become poor or unsafe and cues/supervision necessary at those times
3. **MODERATELY IMPAIRED**—decisions consistently poor or unsafe, cues/supervision required at all times
4. **SEVERELY IMPAIRED**—Never/rarely made decisions
5. **NO DISCERNIBLE CONSCIOUSNESS, COMA** (skip to Section G)

2. MEMORY RECALL ABILITY

Code for recall of what was learned or known

0. Yes, memory OK 1. Memory problem

a. **Short-term memory OK** ☐
- seems/appears to recall after five minutes

b. **Procedural memory OK** ☐
- can perform all or almost all steps in a multitask sequence without cues

c. **Situational memory OK** ☐
- Both; recognises caregiver's name/faces frequently encountered **AND** knows location of places regularly visited (bedroom, dining room, activity room, therapy room)

3. PERIODIC DISORDERED THINKING OR AWARENESS

Note: Accurate assessment requires conversations with staff, family, or others who have direct knowledge of the person's behaviour over time.

0. Behaviour not present
1. Behaviour present, consistent with usual functioning
2. Behaviour present, appears different from usual functioning (e.g. new onset or worsening; different from a few weeks ago)

a. **Easily distracted** ☐
e.g. episodes of difficulty paying attention, gets side-tracked

b. **Episodes of disorganised speech** ☐
e.g. speech is nonsensical, irrelevant, or rambling from subject to subject; loses train of thought

c. **Mental function varies over the course of the day** ☐
e.g. sometimes better, sometimes worse

4. ACUTE CHANGE IN MENTAL STATUS FROM PERSON'S USUAL FUNCTIONING

E.g. restlessness, lethargy, difficulty to arouse, altered environmental perception 0. No 1. Yes ☐

5. CHANGE IN DECISION MAKING

As compared to 90 days ago (or since last assessment)

0. Improved 2. Declined
1. No change 8. Uncertain ☐

SECTION D: COMMUNICATION AND VISION

1. MAKING SELF UNDERSTOOD (EXPRESSION)

Expressing information content–both verbal and non-verbal

0. **UNDERSTOOD**—Expresses ideas without difficulty ☐
1. **USUALLY UNDERSTOOD**—Difficulty finding words or finishing thoughts BUT if given time, little or no prompting usually required
2. **OFTEN UNDERSTOOD**—Difficulty finding words or finishing thoughts AND prompting usually required
3. **SOMETIMES UNDERSTOOD**—Ability is limited to making concrete requests
4. **RARELY/NEVER UNDERSTOOD**

2. ABILITY TO UNDERSTAND OTHERS (COMPREHENSION)

Understanding verbal information content (however able); with hearing aid normally used

0. **UNDERSTANDS**—clear comprehension ☐
1. **USUALLY UNDERSTANDS**—misses some part/intent of message, BUT comprehends most conversation
2. **OFTEN UNDERSTANDS**—misses some part/intent of message BUT with repetition or explanation can often comprehend conversation
3. **SOMETIMES UNDERSTANDS**—responds adequately to simple, direct communication
4. **RARELY/NEVER UNDERSTANDS**

3. HEARING Ability to hear (With hearing aid normally used)

0. **ADEQUATE**—No difficulty in normal conversation, social interaction, listening to TV
1. **MINIMAL DIFFICULTY**—Difficulty in some environments (e.g., when person speaks softly or is more than 2 metres away)
2. **MODERATE DIFFICULTY**—Problem hearing normal conversation, requires quiet setting to hear well
3. **SEVERE DIFFICULTY**—Difficulty in all situations (e.g., speaker has to talk loudly or speak very slowly; or person reports that all speech is mumbled)
4. **NO HEARING**

4. VISION Ability to see in adequate light (with glasses or with other visual aid normally used)

0. **ADEQUATE**—Sees fine detail, including regular print in newspapers/books
1. **MINIMAL DIFFICULTY**—Sees large print, but not regular print in newspapers/books
2. **MODERATE DIFFICULTY**—Limited vision; not able to see newspaper headlines. but can identify objects
3. **SEVERE DIFFICULTY**—Object identification in question, but eyes appear to follow objects; sees only light, colours, shapes
4. **NO VISION**

SECTION E: MOOD AND BEHAVIOUR

1. INDICATORS OF POSSIBLE DEPRESSED, ANXIOUS, SAD MOOD

Code for indicators observed in last 3 days, irrespective of the assumed cause *[Note: whenever possible, ask person.]*

0. Not present
1. Present but not exhibited in last 3 days
2. Exhibited on 1-2 of last 3 days
3. Exhibited daily in last 3 days

a. **MADE NEGATIVE STATEMENTS** e.g. "Nothing matters." "Would rather be dead.", "What's the use.", "Let me die."
b. **PERSISTENT ANGER WITH SELF OR OTHERS** e.g. easily annoyed, anger at care received
c. **EXPRESSIONS, INCLUDING NONVERBAL, OF WHAT APPEAR TO BE UNREALISTIC FEARS** e.g., fear of being abandoned, left alone, or being with others; intense fear of specific objects or situations
d. **REPETITIVE HEALTH COMPLAINTS** e.g., persistently seeks medical attention, incessant concern with body functions
e. **REPETITIVE ANXIOUS COMPLAINTS/CONCERNS** non health-related e.g., persistently seeks attention/ reassurance regarding schedules, meals, laundry, clothing, relationships
f. **SAD, PAINED, WORRIED FACIAL EXPRESSIONS** e.g., furrowed brow, constant frowning
g. **CRYING, TEARFULNESS**
h. **RECURRENT STATEMENTS THAT SOMETHING TERRIBLE IS ABOUT TO HAPPEN** e.g., believes he or she is about to die, have a heart attack
i. **WITHDRAWAL FROM ACTIVITIES OF INTEREST** e.g., no interest in long standing activities or being with family or friends
j. **REDUCED SOCIAL INTERACTION**
k. **EXPRESSIONS, INCLUDING NONVERBAL, OF A LACK OF PLEASURE IN LIFE (ANHEDONIA)** e.g., "I don't enjoy anything anymore."

2. SELF-REPORTED MOOD

0. Not in the last 3 days
1. Not in the last 3 days, but often feels that way
2. In 1-2 of the last 3 days
3. Daily in the last 3 days
8. Person could not (would not) respond

Ask: "In the last 3 days, how often have you felt..."

a. Little interest or pleasure in things you normally enjoy?
b. Anxious, restless, or uneasy?
c. Sad, depressed, or hopeless?

3. BEHAVIOURAL SYMPTOMS

Code for indicators observed, irrespective of the assumed cause

0. Not present
1. Present but not exhibited in last 3 days
2. Exhibited on 1–2 of last 3 days
3. Exhibited daily in last 3 days

a. **WANDERING** moving with no rational purpose, seemingly oblivious to needs or safety
b. **VERBAL ABUSE** others were threatened, screamed at cursed at
c. **PHYSICAL ABUSE** Others were hit, shoved, scratched sexually abused
d. **SOCIALLY INAPPROPRIATE/DISRUPTIVE BEHAVIOUR** made disruptive sounds or noises, screamed out, smeared or threw food or faeces, hoarded, rummaged through other's belongings
e. **INAPPROPRIATE PUBLIC SEXUAL BEHAVIOUR OR PUBLIC DISROBING**
f. **RESISTS CARE** taking medications/injections, ADL assistance, eating

SECTION F: PSYCHOSOCIAL WELL-BEING

1. SOCIAL RELATIONSHIPS *[Note: Whenever possible, ask person]*

0. Never
1. More than 30 days ago
2. 8–30 days ago
3. 4-7days ago
4. In last 3 days
8. Unable to determine

a. Participation in social activities of long-standing interest
b. Visit with a long-standing social relation or family member
c. Other interaction with long-standing social relation or family member—e.g., telephone, e-mail
d. Conflict or anger with family or friends
e. Fearful of a family member or close acquaintance
f. Neglected, abused, or mistreated

2. LONELY

Says or indicates that he/she feels lonely 0. No 1. Yes

3. CHANGE IN SOCIAL ACTIVITIES IN LAST 90 DAYS *[or since last assessment if less than 90 days ago]*

Decline in level of participation in social, religious, occupational, or other preferred activities. IF THERE WAS A DECLINE, person distressed by this fact.

0. No Decline
1. Decline, not distressed
2. Decline, distressed

4. LENGTH OF TIME ALONE DURING THE DAY

Morning and afternoon

0. Less than 1 hour
1. 1-2 hours
2. More than 2 hours but less than 8 hours
3. 8 hours or more

5. MAJOR LIFE STRESSORS IN LAST 90 DAYS

e.g. episode of severe personal illness; death or severe illness of close

family member/friend; loss of home; major loss of income/assets; victim of a crime such as robbery; loss of driving license/car

0. No 1. Yes ☐

SECTION G: FUNCTIONAL STATUS

1. IADL SELF-PERFORMANCE AND CAPACITY

0. **INDEPENDENT**—No help, setup, or supervision
1. **SETUP HELP ONLY**
2. **SUPERVISION**—Oversight/cuing
3. **LIMITED ASSISTANCE**—Help on some occasions
4. **EXTENSIVE ASSISTANCE**—Help throughout task, but performs 50% or more of task on own
5. **MAXIMAL ASSISTANCE**—Help throughout task, but performs less than 50% of task on own
6. **TOTAL DEPENDENCE**—Full performance by others during entire period
8. **ACTIVITY DID NOT OCCUR DURING ENTIRE PERIOD** ** do not use this for coding (B) CAPACITY*

	(A) PERFORMANCE	(B) CAPACITY
(A) Code for **PERFORMANCE** in routine activities around the home or in the community during the LAST 3 DAYS. **(B)** Code for **CAPACITY** based on presumed ability to carry out activity as independently as possible. This will require "speculation" by the assessor.		
a. **MEAL PREPARATION** How meals are prepared (e.g., planning meals, cooking, assembling ingredients, setting out food and utensils)	☐	☐
b. **ORDINARY HOUSEWORK** How ordinary work around the house is performed (e.g., doing dishes, dusting, making bed, tidying up, laundry)	☐	☐
c. **MANAGING FINANCES** How bills are paid, cheque book is balanced, household expenses are budgeted, credit card account is monitored	☐	☐
d. **MANAGING MEDICATIONS** How medications are managed (e.g., remembering to take medicines, opening bottles, taking correct drug dosages, giving injections, applying ointments)	☐	☐
e. **PHONE USE** How telephone calls are made or received (with assistive devices such as large numbers on telephone, amplification as needed)	☐	☐
f. **STAIRS** How full flight of stairs is managed (12–14 stairs)	☐	☐
g. **SHOPPING** How shopping is performed for food and household items (e.g., selecting items, paying money) EXCLUDE TRANSPORTATION	☐	☐
h. **TRANSPORTATION** How travels by public transportation (navigating system, paying fare) or driving self (including getting out of house, into and out of vehicles)	☐	☐

2. ADL SELF-PERFORMANCE

Consider all episodes over 3-day period

0. **INDEPENDENT**—No physical assistance, setup, or supervision in any episode
1. **INDEPENDENT, SETUP HELP ONLY**—Article or device provided or placed within reach, no physical assistance or supervision in any episode
2. **SUPERVISION**—Oversight/cuing
3. **LIMITED ASSISTANCE**—Guided manoeuvring of limbs, physical guidance without taking weight
4. **EXTENSIVE ASSISTANCE**—Weight-bearing support (including lifting limbs) by 1 helper where person still performs 50% or more of subtasks
5. **MAXIMAL ASSISTANCE**—Weight-bearing support (including lifting limbs) by 2+ helpers—OR—Weight-bearing support for more than 50% of subtasks
6. **TOTAL DEPENDENCE**—Full performance by others during all episodes
8. **ACTIVITY DID NOT OCCUR DURING ENTIRE PERIOD**

If all episodes are performed at the same level, score ADL at that level.

If any episodes at level 6, and others less dependent, score ADL as a 5.

Otherwise, focus on the three most dependent episodes [or all episodes if performed fewer than 3 times] If most dependent episode is 1, score ADL as 1. If not, score ADL as least dependent of those episodes in range 2–5.

a. **BATHING** How takes full-body bath/shower. Includes how transfers in and out of bath or shower AND how each part of body is bathed: arms, upper and lower legs, chest, abdomen, perineal area - EXCLUDE WASHING OF BACK AND HAIR	☐
b. **PERSONAL HYGIENE** How manages personal hygiene, including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands EXCLUDE BATHS AND SHOWERS	☐
c. **DRESSING UPPER BODY** How client dresses and undresses (street clothes, underwear) above the waist, included prostheses, orthotics, fasteners, pullovers, etc.	☐
d. **DRESSING LOWER BODY** How client dresses and undresses (street clothes, underwear) from the waist down, includes prostheses, orthotics, belts, pants, skirts, shoes, and fasteners	☐
e. **WALKING** How walks between locations on same floor indoors	☐
f. **LOCOMOTION** How moves between locations on same floor (walking or wheeling). If in wheelchair, self-sufficiency once in chair	☐
g. **TRANSFER TOILET** How moves on and off toilet or commode	☐
h. **TOILET USE** How uses the toilet room (or commode, bedpan, urinal), cleans self after toilet use or incontinent episode(s), changes pad, manages ostomy or catheter, adjusts clothes EXCLUDES TRANSFER ON AND OFF TOILET	☐
i. **BED MOBILITY** How moves to and from lying position, turns from side to side, and positions body while in bed	☐
j. **EATING** How eats and drinks (regardless of skill). Includes intake of nourishment by other means (e.g., tube feeding, total parenteral nutrition)	☐

3. LOCOMOTION/WALKING

a. PRIMARY MODE OF LOCOMOTION

0. Walking, no assistive device
1. Walking, uses assistive device—walking stick, walker, crutch, pushing wheelchair
2. Wheelchair, scooter
3. Bed-bound

b. TIMED 4 METRE WALK

Lay out a straight, unobstructed course. Have person stand in still position, feet just touching start line.

Then say: "When I tell you, begin to walk at a normal pace (with walking stick / walker if used). This is not a test of how fast you can walk. Stop when I tell you to stop. Is this clear?" Assessor may demonstrate test.

Then say: "Begin to walk now." Start stopwatch (or can count seconds) when first foot falls. End count when foot falls beyond 4-metre mark.

Then say: "You may stop now."

Enter time in seconds, up to 30 seconds

30. 30 or more seconds to walk 4 metres
77. Stopped before test complete
88. Refused to do the test
99. Not tested–e.g., does not walk on own

c. DISTANCE WALKED

Farthest distance walked at one time without sitting down in the LAST 3 DAYS (with support as needed)

0. Did not walk
1. Less than 5 metres
2. 5–49 metres
3. 50–99 metres
4. 100+ metres
5. 1+ kilometres

d. DISTANCE WHEELED SELF

Farthest distance wheeled self at one time in the LAST 3 DAYS (includes independent use of motorised wheelchair).

0. Wheeled by others
1. Used motorised wheelchair / scooter
2. Wheeled self less than 5 metres
3. Wheeled self 5-49 metres
4. Wheeled self 50-99 metres
5. Wheeled self 100+ metres
8. Did not use wheelchair

4. ACTIVITY LEVEL

a. Total hours of exercise or physical activity in LAST 3 DAYS e.g. walking

0. None
1. Less than 1 hour
2. 1–2 hours
3. 3–4 hours
4. More than 4 hours

b. In the LAST 3 DAYS, number of days went out of the house or building in which he / she resides (no matter how short the period)

0. No days out
1. Did not go out in last 3 days, but usually goes out over a 3-day period
2. 1–2 days
3. 3 days

5. PHYSICAL FUNCTION IMPROVEMENT POTENTIAL

a. Person believes he / she is capable of improved performance in physical function 0. No 1. Yes

b. Health professional believes person is capable of improved performance in physical function 0. No 1. Yes

6. CHANGE IN ADL STATUS

As compared to 90 days ago, or since last assessment if less than 90 days ago

0. Improved
1. No change
2. Declined
8. Uncertain

7. DRIVING

a. Drove car (vehicle) in the LAST 90 DAYS 0. No 1. Yes

b. If drove in LAST 90 DAYS, assessor is aware that someone has suggested that person limits OR stops driving 0. No 1. Yes

SECTION H: CONTINENCE

1. BLADDER CONTINENCE

0. **CONTINENT**—Complete control; DOES NOT USE any type of catheter or urinary collection device
1. **CONTINENT WITH CATHETER**— Control with any catheter or ostomy over the last 3 days
2. **INFREQUENTLY INCONTINENT**— Not incontinent over last 3 days, but does have incontinent episodes
3. **OCCASIONALLY INCONTINENT**—Less than Daily
4. **FREQUENTLY INCONTINENT**—Daily, but some control present
5. **INCONTINENT**—No control present
8. **DID NOT OCCUR**—No urine output from bladder in last 3 days

2. URINARY COLLECTION DEVICE *[Excludes pads/briefs]*

0. None
1. Urodome
2. Indwelling catheter
3. Cystostomy, nephrostomy, ureterostomy

3. BOWEL CONTINENCE

0. **CONTINENT**—Complete control; DOES NOT USE ostomy device
1. **CONTINENT WITH OSTOMY**— Control with ostomy device over the last 3 days
2. **INFREQUENTLY INCONTINENT** — Not incontinent over last 3 days, but does have incontinent episodes
3. **OCCASIONALLY INCONTINENT**—Less than daily
4. **FREQUENTLY INCONTINENT**—Daily, but some control present
5. **INCONTINENT**—No control present
8. **DID NOT OCCUR**—No bowel movement in the last 3 days

4. PADS OR BRIEFS WORN 0. No 1. Yes

SECTION I: DISEASE DIAGNOSES

1. DISEASES

Disease/infection that doctor has indicated is present and affects client's status, requires treatment, or symptom management. Also include if disease is monitored by a home care professional or is the reason for a hospitalization in LAST 90 DAYS (or since last assessment if less than 90 days)

0. Not present
1. Primary diagnosis/diagnoses for current stay
2. Diagnosis present, receiving active treatment
3. Diagnosis present, monitored but no active treatment

MUSCULO-SKELETAL

a. Hip fracture during last 30 days (or since last assessment if less than 30 days)

b. Other fracture during last 30 days (or since last assessment if less than 30 days)

NEUROLOGICAL

c. Alzheimer's disease

d. Dementia other than Alzheimer's disease ☐
e. Hemiplegia ☐
f. Multiple sclerosis ☐
g. Paraplegia ☐
h. Parkinson's disease ☐
i. Quadriplegia ☐
j. Stroke/CVA ☐

CARDIAC OR PULMONARY

k. Coronary heart disease ☐
l. Chronic obstructive pulmonary disease ☐
m. Congestive heart failure ☐

PSYCHIATRIC

n. Anxiety ☐
o. Bipolar disorder ☐
p. Depression ☐
q. Schizophrenia ☐

INFECTIONS

r. Pneumonia ☐
s. Urinary tract infection in last 30 days ☐

OTHER

t. Cancer ☐
u. Diabetes mellitus ☐

2. OTHER DISEASE

0. Not present
1. Primary diagnosis/diagnoses for current stay
2. Diagnosis present, receiving active treatment
3. Diagnosis present, monitored but no active treatment

DIAGNOSIS	DISEASE CODE	ICD CODE
a.		
b.		
c.		
d.		

SECTION J: HEALTH CONDITIONS

1. FALLS

0. No fall in last 90 days ☐
1. No fall in last 30 days, but fell 31–90 days ago
2. One fall in last 30 days
3. Two or more falls in last 30 days

2. RECENT FALLS

[Skip / not applicable if last assessed more than 30 days ago or if this is first assessment] 0. No 1. Yes ☐

3. PROBLEM FREQUENCY

Code for presence in last 3 days

0. Not present
1. Present but no exhibited in last 3 days
2. Exhibited on 1 of last 3 days
3. Exhibited on 2 of last 3 days
4. Exhibited daily in last 3 days

BALANCE

a. Difficult or unable to move self to standing position unassisted ☐
b. Difficult or unable to turn self around and face the opposite direction when standing ☐
c. Dizziness ☐
d. Unsteady gait ☐

CARDIAC OR PULMONARY

e. Chest pain ☐
f. Difficulty clearing airway secretions ☐

PSYCHIATRIC

g. Abnormal thought process—e.g., loosening of associations, blocking, flight of ideas, tangentiality, circumstantiality ☐
h. Delusions—Fixed, false beliefs ☐
i. Hallucinations—False sensory perceptions ☐

NEUROLOGICAL

j. Aphasia ☐

GI STATUS

k. Acid reflux—Regurgitation of acid from stomach to throat ☐
l. Constipation—No bowel movement in 3 days or difficult passage of hard stool ☐
m. Diarrhoea ☐
n. Vomiting ☐

SLEEP PROBLEMS

o. Difficulty falling asleep or staying asleep; waking up too early; restlessness; non-restful sleep ☐
p. Too much sleep—Excessive amount of sleep that interferes with person's normal functioning ☐

OTHER

q. Aspiration ☐
r. Fever ☐
s. GI or GU bleeding ☐
t. Hygiene - unusually poor hygiene, unkempt, dishevelled ☐
u. Peripheral oedema ☐

4. DYSPNOEA (SHORTNESS OF BREATH)

0. Absence of symptom ☐
1. Absent at rest, but present when performed moderate activities
2. Absent at rest, but present when performed normal day-to-day activities
3. Present at rest

5. FATIGUE

Inability to complete normal daily activities—e.g., ADLs, IADLs

0. None
1. Minimal– Diminished energy but completes normal day-to-day activities
2. Moderate–Due to diminished energy, UNABLE TO FINISH normal day-to-day activities
3. Severe—Due to diminished energy, UNABLE TO START SOME normal day-to-day activities
4. Unable to commence any normal day-to-day activities–Due to diminished energy

6. PAIN SYMPTOMS

[Note: Always ask the person about pain frequency, intensity, and control. Observe person and ask others who are in contact with the person.]

a. Frequency with which person complains or shows evidence of pain *[including grimacing, teeth clenching, moaning, withdrawal when touched, or other nonverbal signs suggesting pain]*

0. No pain
1. Present but not exhibited in last 3 days
2. Exhibited on 1–2 of last 3 days
3. Exhibited daily in last 3 days

b. Intensity of highest level of pain present

0. No pain
1. Mild
2. Moderate
3. Severe
4. Times when pain is horrible or excruciating

c. Consistency of pain

0. No pain
1. Single episode during last 3 days
2. Intermittent
3. Constant

d. Breakthrough pain 0. No 1. Yes

Times in LAST 3 DAYS when person experienced sudden, acute flare-ups of pain

e. Pain control

Adequacy of current therapeutic regimen to control pain (from person's point of view)

0. No issue of pain
1. Pain intensity acceptable to person; no treatment regimen or change in regimen required
2. Controlled adequately by therapeutic regimen
3. Controlled when therapeutic regimen followed, but not always followed as ordered
4. Therapeutic regimen followed, but pain control not adequate
5. No therapeutic regimen being followed for pain; pain not adequately controlled

7. INSTABILITY OF CONDITIONS 0. No 1. Yes

a. Conditions / diseases make cognitive, ADL, mood, or behaviour patterns unstable (fluctuating, precarious, or deteriorating)

b. Experiencing an acute episode, or a flare-up of a recurrent or chronic problem

c. End-stage disease, 6 or fewer months to live.

8. SELF-REPORTED HEALTH

Ask: "In general, how would you rate your health?"

0. Excellent 2. Fair 8. Could not (would not) respond
1. Good 3. Poor

9. TOBACCO AND ALCOHOL

a. Smokes tobacco daily

0. No
1. Not in last 3 days, but is usually a daily smoker
2. Yes

b. Alcohol—Highest number of drinks in any "single sitting" in LAST 14 DAYS

0. None 2. 2–4
1. 1 3. 5 or more

SECTION K: ORAL AND NUTRITIONAL STATUS

1. HEIGHT AND WEIGHT

a. Record **HEIGHT** in centimetres

b. Record **WEIGHT** in kilograms. Base weight on most recent measure taken in LAST 30 DAYS

2. NUTRITIONAL ISSUES 0. No 1. Yes

[Note: NZ assessors we do not use the BUN/Creatinine measures]

a. Weight loss of 5% or more in LAST 30 DAYS, or 10% or more in LAST 180 DAY

b. Dehydrated, or BUN / Cre Ratio >25

c. Fluid intake less than 1,000 cc per day

d. Fluid output exceeds input

e. Decrease in amount of food or fluid usually consumed

f. Ate one or fewer meals on AT LEAST 2 of LAST 3 DAYS

3. MODE OF NUTRITIONAL INTAKE

0. **NORMAL** Swallows all types of food
1. **MODIFIED INDEPENDENT** e.g., liquid is sipped, takes limited solid food; need for modification may be unknown
2. **REQUIRES DIET MODIFICATION TO SWALLOW SOLID FOOD** e.g., mechanical diet (puree, minced, etc.) or only able to ingest specific food
3. **REQUIRES MODIFICATION TO SWALLOW LIQUIDS** e.g., thickened liquids
4. **CAN SWALLOW ONLY PUREED SOLIDS AND THICKENED LIQUIDS**
5. **COMBINED ORAL AND PARENTERAL OR TUBE FEEDING**
6. **NASOGASTRIC TUBE FEEDING ONLY**
7. **ABDOMINAL FEEDING TUBE** e.g., PEG tube
8. **PARENTERAL FEEDING ONLY** Includes all types of parenteral feedings, such as total parenteral nutrition (TPN)
9. **ACTIVITY DID NOT OCCUR** During entire period

4. DENTAL OR ORAL 0. No 1. Yes

a. Wears a denture (removable prosthesis)

b. Has broken, fragmented, loose, or otherwise non-intact natural teeth

c. Reports having dry mouth

d. Reports difficulty chewing ☐

SECTION L: SKIN CONDITION

1. MOST SEVERE PRESSURE ULCER

0. No pressure ulcer
1. Any area of persistent skin redness
2. Partial loss of skin layers
3. Deep craters in the skin
4. Breaks in skin exposing muscle or bone
5. Not codeable, e.g., necrotic eschar predominant

2. PRIOR PRESSURE ULCER 0. No 1. Yes

3. PRESENCE OF SKIN ULCER OTHER THAN PRESSURE ULCER

E.g., venous ulcer, arterial ulcer, mixed venous-arterial ulcer, diabetic foot ulcer 0. No 1. Yes

4. MAJOR SKIN PROBLEMS 0. No 1. Yes

E.g., lesions, 2nd- or 3rd-degree burns, healing surgical wound

5. SKIN TEARS OR CUTS Other than surgery 0. No 1. Yes

6. OTHER SKIN CONDITIONS OR CHANGES IN SKIN CONDITION

E.g., bruises, rashes, itching, mottling, herpes zoster, intertrigo, eczema 0. No 1. Yes

7. FOOT PROBLEMS

E.g., bunions, hammertoes, overlapping toes, structural problems, infections, ulcers

0. No Foot Problems
1. Foot Problems, no limitation in walking
2. Foot problems limit walking
3. Foot Problems prevent walking
4. Foot problems, does not walk for other reasons

SECTION M: MEDICATIONS

1. ALLERGY TO ANY DRUG

0. No known drug allergies 1. Yes

2. ADHERENT WITH MEDICATIONS PRESCRIBED BY PHYSICIAN

0. Always adherent
1. Adherent 80% of time or more
2. Adherent less than 80% of time, including failure to purchase prescribed medications
3. No medications prescribed

3. LIST OF ALL MEDICATIONS

List all active prescriptions and nonprescribed (over-the-counter) medications taken in the LAST 3 DAYS
Note: Use computerised records if possible, hand enter only when absolute necessary. FOR EACH DRUG RECORD:

a. NAME

b. DOSE—A positive number such as 0.5, 5, 150, 300. [Note: Never write a zero by itself after a decimal point (X.0 mg)]

c. UNIT—Code using the following list:

gtts (drops)
gm (grams)
L (litres)
mcg (micrograms)
mEq (milli-equivalent)
mg (milligrams)
ml (millilitres)
oz (ounces)
puffs
% (percent)
units
oth (other)

d. ROUTE OF ADMINISTRATION—Code using the following list:

PO (By mouth)
SL (Sub lingual)
IM (Intramuscular)
IV (Intravenous)
SQ (Subcutaneous)
EYE (eye)
TOP (Topical)
IH (Inhalation)
ET (Enteral tube)
R (Rectal)
TD (transdermal)
NAS (nasal)
Other

e. FREQ—Code the number of times per day, week, or month the medication is administered using the following list:

Q1H. Every hour
Q2H. Every two hours
Q3H. Every three hours
Q4H. Every four hours
Q6H. Every six hours
Q8H. Every eight hours
5D. Five times daily
BED Bedtime
BID. Two times daily
TID. Three times daily
QID. Four times daily
Q2D. Every other day
Q3D. Every three days
Weekly. Once each week
2W. Two times weekly
3W. Three times weekly
4W. Four times weekly
5W. Five times weekly
6W. Six times weekly
1M. Monthly
2M. Twice every month
OTH. Other

a. Medication Name	b. Dose	c. Unit	d. Route	e. Freq	f. PRN	g. Drug

f. PRN **g. COMPUTER-ENTERED DRUG CODE**

SECTION N: TREATMENT AND PROCEDURES

1. PREVENTION 0. No 1. Yes

a. Blood pressure measured in LAST YEAR ☐
b. Colonoscopy test in LAST 5 YEARS ☐
c. Dental exam in LAST YEAR ☐
d. Eye exam in LAST YEAR ☐
e. Hearing exam in LAST 2 YEARS ☐
f. Influenza vaccine in LAST YEAR ☐
g. Mammogram or breast exam in LAST 2 YEARS (for women) ☐
h. Pneumovax vaccine in LAST 5 YEARS or after age 65 ☐

2. TREATMENTS AND PROGRAMMES RECEIVED OR SCHEDULED IN THE LAST 3 DAYS *[or since last assessment if less than 3 days]*

0. Not ordered AND did not occur
1. Ordered, not implemented
2. 1–2 of last 3 days
3. Daily in last 3 days

TREATMENTS

a. Chemotherapy ☐ h. Tracheostomy care ☐

b.	Dialysis	☐	i. Transfusion	☐
c.	Infection control e.g., isolation, quarantine	☐	j. Ventilator or respirator	☐
d.	IV medication	☐	k. Wound care	☐
e.	Oxygen therapy	☐	**PROGRAMMES**	
f.	Radiation	☐	l. Scheduled toileting programme	☐
g.	Suctioning	☐	m. Palliative care programme	☐
			n. Turning/repositioning programme	☐

3. FORMAL CARE

Days (A) and Total minutes (B) of care in last 7 days.

Extent of care/treatment in LAST 7 DAYS *[or since last assessment or admission, if less than 7 days]*involving:

		(A) Days	(B) Mins
a.	Personal care / support services	☐☐	☐☐☐
b.	Visiting nurses	☐☐	☐☐☐
c.	Household management services	☐☐	☐☐☐
d.	Meals	☐☐	■■■
e.	Physiotherapy	☐☐	☐☐☐
f.	Occupational therapy	☐☐	☐☐☐
g.	Speech-language therapy services	☐☐	☐☐☐
h.	Psychological therapy (by any licensed mental health professional)	☐☐	☐☐☐

4. HOSPITAL USE EMERGENCY ROOM USE PHYSICIAN VISIT

Code for number of times in LAST 90 DAYS *[or since last assessment if LESS THAN 90 DAYS]*

a.	Inpatient acute care hospital with overnight stay	☐☐
b.	Emergency room visit (not counting overnight stay)	☐☐
c.	Physician visit (or authorised assistant or practitioner)	☐☐

5. PHYSICALLY RESTRAINED

Limbs restrained, used bed rails, restrained to chair when sitting ☐

0. No 1. Yes

SECTION O: RESPONSIBILITY

1. RESPONSIBILITY / LEGAL GUARDIAN 0. No 1. Yes

a.	EPOA for personal care and welfare	☐
b.	EPOA for property	☐

2. ADVANCE DIRECTIVES 0. Not in place 1. In place

a.	Living will	☐
b.	Do not resuscitate	☐
c.	Do not hospitalise	☐
d.	Organ donation	☐
e.	Post mortem request	☐
f.	Feeding restrictions	☐
g.	Medication restrictions	☐
h.	Other treatment restrictions	☐

SECTION P: SOCIAL SUPPORTS

1. TWO KEY INFORMAL HELPERS

a. Relationship to person — Helper 1 ☐ 2 ☐

1. Child or child-in-law
2. Spouse
3. Partner/significant other
4. Parent/guardian
5. Sibling
6. Other relative or whanau
7. Friend
8. Neighbour
9. No informal helper

b. Lives with person — Helper 1 ☐ 2 ☐

0. No
1. Yes, 6 months or less
2. Yes, more than 6 months
8. No informal helper

AREAS OF INFORMAL HELP DURING LAST 3 DAYS

0. No
1. Yes
8. No informal helper

c. IADL help ☐☐

d. ADL help ☐☐

2. INFORMAL HELPER STATUS 0. No 1. Yes

a.	Informal helper(s) is unable to continue caring activities—e.g., decline in health of helper makes it difficult to continue	☐
b.	Primary informal helper expresses feelings of distress, anger, or depression	☐
c.	Family or close friends report feeling overwhelmed by person's illness	☐

3. HOURS OF INFORMAL CARE AND ACTIVE MONITORING DURING LAST 3 DAYS

For instrumental and personal activities of daily living in the LAST 3 DAYS, indicate the total number of hours of help received from all family, friends, and neighbours ☐☐☐

4. STRONG AND SUPPORTIVE RELATIONSHIP WITH FAMILY

0. No 1. Yes ☐

SECTION Q: ENVIRONMENTAL ASSESSMENT

1. HOME ENVIRONMENT

Code for any of the following that make home environment hazardous or uninhabitable (if temporarily in institution, base assessment on home visits 0. No 1. Yes

a. Disrepair of the home—e.g., hazardous clutter; inadequate or no lighting in living room, sleeping room, kitchen, toilet, corridors; holes in floor; leaking pipes ☐

b. Squalid condition—e.g., extremely dirty, infestation by rats or bugs ☐

c. Inadequate heating or cooling—e.g., too hot in summer, too cold in winter ☐

d. Lack of personal safety—e.g., fear of violence, safety problem in going to mailbox or visiting neighbours, heavy traffic in street ☐

e. Limited access to home or rooms in home—e.g., difficulty entering or leaving home, unable to climb stairs, difficulty manoeuvring within rooms, no railings although needed ☐

2. LIVES IN APARTMENT OR HOUSE RE-ENGINEERED ACCESSIBLE FOR PERSONS WITH DISABILITIES 0. No 1. Yes ☐

3. OUTSIDE ENVIRONMENT 0. No 1. Yes

a. Availability of emergency assistance—e.g., telephone, alarm response system ☐

b. Accessibility to grocery store without assistance ☐

c. Availability of home delivery of groceries ☐

4. FINANCES

Because of limited funds, during the last 30 days made trade-offs among purchasing any of the following: adequate food, shelter, clothing; prescribed medications; sufficient home heat or cooling; necessary health care 0. No 1. Yes ☐

SECTION R: DISCHARGE POTENTIAL AND OVERALL STATUS

1. ONE OR MORE CARE GOALS MET IN THE LAST 90 DAYS

(Or since last assessment if less than 90 days)

0. No 1. Yes ☐

2. OVERALL SELF- SUFFICIENCY HAS CHANGED SIGNIFICANTLY AS COMPARED TO STATUS OF 90 DAYS AGO

(Or since last assessment if less than 90 days) ☐

0. Improved [skip to Section S]
1. No change [skip to section S]
2. Deteriorated

CODE FOLLOWING THREE ITEMS IF "DETERIORATED" IN LAST 90 DAYS—OTHERWISE SKIP TO SECTION S

3. NUMBER OF 10 ADL AREAS IN WHICH PERSON WAS INDEPENDENT PRIOR TO DETERIORATION ☐

4. NUMBER OF 8 IADL PERFORMANCE AREAS IN WHICH PERSON WAS INDEPENDENT PRIOR TO DETERIORATION ☐

5. TIME OF ONSET OF THE PRECIPITATING EVENT OR PROBLEM RELATED TO DETERIORATION ☐

0. Within last 7 days
1. 8 to 14 days ago
2. 15 to 30 days ago
3. 31 to 60 days ago
4. More than 60 days ago
8. No clear precipitating event

SECTION S: DISCHARGE

1. LAST DAY OF STAY

Date of discharge ☐☐☐☐☐☐☐☐

2. RESIDENTIAL / LIVING STATUS AFTER DISCHARGE ☐

1. Private home/apartment/rented room
2. Board and care
3. Assisted living or semi-independent living
4. Mental health residence—e.g., psychiatric group home
5. Group home for persons with physical disability
6. Setting for persons with intellectual disability
7. Psychiatric hospital or unit
8. Homeless (with or without shelter)
9. Long-term care facility (nursing home)
10. Rehabilitation hospital/unit
11. Hospice facility/palliative care unit
12. Acute care hospital
13. Correctional facility
14. Other
15. Deceased

SECTION T: ASSESSMENT INFORMATION

SIGNATURE OF PERSON COORDINATING/COMPLETING THE ASSESSMENT

DATE ASSESSMENT SIGNED AS COMPLETE

☐☐☐☐☐☐☐☐

Appendix B: Health and Disability Ethics Committee

Health and Disability Ethics Committees
Ministry of Health
Freyberg Building
20 Aitken Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

11 October 2016

Dr Hamish Jamieson
The Princess Margaret Hospital
Cashmere Rd
Christchurch 8140

Dear Dr Jamieson

Re:	**Ethics ref:**	**14/STH/140/AM06**
	Study title:	Understanding health conditions and outcomes in older people

I am pleased to advise that this amendment has been ***approved*** by the Southern Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Ms Raewyn Idoine
Chairperson
Southern Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted and approved

Document	Version	Date
Protocol	1	27 May 2016
Post Approval Form	1	-

Appendix B
Statement of compliance and list of members

Statement of compliance

The Southern Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008713) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Ms Raewyn Idoine	Lay (consumer/community perspectives)	27/10/2015	27/10/2018
Dr Devonie Eglinton	Non-lay (intervention studies)	13/05/2016	13/05/2019
Mrs Angelika Frank-Alexander	Lay (consumer/community perspectives)	27/10/2015	27/10/2018
Dr Sarah Gunningham	Non-lay (intervention studies)	27/10/2015	27/10/2018
Assc Prof Mira Harrison-Woolrych	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Fiona McCrimmon	Lay (the law)	27/10/2015	27/10/2018
Dr Nicola Swain	Non-lay (observational studies)	27/10/2015	27/10/2018
Dr Mathew Zacharias	Non-lay (health/disability service provision)	27/10/2015	27/10/2018

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

http://www.ethics.health.govt.nz

Appendix C: Ngai Tahu Consultation and Engagement

Ngāi Tahu Consultation and Engagement Group

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

02/04/2017

Tēnā koe, Babajide

RE: Prognostic Stratification of Functional Decline in the Elderly with Chronic Obstructive Pulmonary Disease: Transitioning from the Community to Long Term Care

This letter is written on behalf of the Ngāi Tahu Consultation and Engagement Group. I/We have read and considered your proposal and acknowledge that this is a worthwhile and interesting project there have been no issues identified.

It is well considered and the researcher is clear about how they ought to take participants' (cultural) needs into account if and when applicable.

Thank you for engaging with the Māori consultation process. This will strengthen your research proposal, support the University's Strategy for Māori Development, and increase the likelihood of success with external engagement. It will also increase the likelihood that the outcomes of your research will be of benefit to Māori communities. We wish you all the best with your current project and look forward to hearing about future research plans.

The Ngāi Tahu Consultation and Engagement Group would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any questions.

Ngā mihi
Nigel Harris

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